Setting the stage for death

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Setting the stage for death

New themes in the euthanasia debate

Mette Rurup

The studies presented in this thesis were performed at the Institute for Research in Extramural Medicine (EMGO Institute) at the Department of Public and Occupational Health, the Department of Nursing Home Medicine and the Department of Psychiatry of the VU University Medical Center in Amsterdam, and the Department of Public Health, of the Erasmus MC in Rotterdam. The EMGO Institute participates in the Netherlands School of Primary Care Research (CaRe), which has been acknowledged by the Royal Dutch Academy of Science (KNAW).

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SETTING THE STAGE FOR DEATH

New themes in the euthanasia debate

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Voor Pieter

CONTENTS

Part 1

Introduction

1.1 NEW ISSUES IN PHYSICIAN-ASSISTED DEATH

In the Netherlands, euthanasia has become an accepted practice over the past few decades, and it is now endorsed by law, the medical profession and public opinion. Although the legalization of euthanasia has been discussed in many countries, this development was unique for the Netherlands, and until recently, no similar developments had been reported in any other country in the world. However, there is now also legislation concerning euthanasia or assisted suicide in Belgium and in the state of Oregon in the USA, and the United Kingdom is currently considering euthanasia legislation (Onwuteaka-Philipsen *et al.* 2005*)*. However, there does not seem to be any trend that other countries will follow the Dutch example in the near future. Why this development took place in the Netherlands, and not in other countries, has been the subject of discussion. Kennedy has tried to explain it as a result of the typically Dutch culture in the seventies of discussing everything openly, getting rid of taboos, and not trying to stop 'inevitable' changes but trying to discuss and regulate them (Kennedy, 2002). All countries have to deal with the negative consequences of increasing medical possibilities: being able to keep seriously ill people alive much longer also means extending their suffering. Most countries have only focussed on improving palliative care for these patients, but the Netherlands has also focussed on legalizing euthanasia as the only real escape for patients whose suffering cannot be adequately alleviated, and for some patients euthanasia is considered to be the only way of escaping the pointlessness of the degrading dying process.

According to Kennedy, in the Netherlands euthanasia was considered to be more than just a medical act based on alleviating physical suffering, it was an act of compassion and humanity. Indeed, although it was debated, the terminal phase of a disease was not included as a requirement for euthanasia, and the justification of euthanasia was based on the autonomy of the patient and the extent of suffering. One of the consequences is that granting a request for euthanasia from a patient who is paralysed can be legal under certain circumstances. There are other consequences of the absence of a terminal stage as a requirement that have led to serious debate: should euthanasia be allowed in the absence of a severe disease, if people are 'weary of life', and should euthanasia be allowed in the advanced stages of dementia if the patient has an advance euthanasia directive? Although there is considerable debate about these issues, this is mostly theoretical, and is mainly based on a few case descriptions. However, it is not known whether or not this theoretical debate reflects daily practice. The aim of this thesis is to fill this gap in our knowledge by answering the following research questions:

- How many people request euthanasia or assisted suicide (EAS)[a] because they are 'weary of life', what are the characteristics of these people, and how often do physicians grant such requests?
- What do physicians and the general public think about EAS in the absence of a severe disease, and a 'suicide pill' for older people?
- How many patients have an advance directive concerning euthanasia, and what are physicians' experiences with demented patients who have an advance euthanasia directive?

[a] Euthanasia is usually defined in the Netherlands as the administration of drugs by a physician with the explicit intention of ending the patient's life at his/her explicit request. Physician-assisted suicide is usually defined as the prescription or supply of drugs at the explicit request of the patient with the explicit intention to enable the patient to end his/her own life. In the context of patients who do not have a severe disease, it might be more logical to talk about requests for assistance with suicide, but since physician-assisted suicide is not a commonly known term in the Netherlands, we will use the term 'euthanasia or assisted suicide' (EAS) in this thesis.

- What are the attitudes of physicians, nurses and relatives of patients suffering from dementia concerning advance euthanasia directives and other end-of-life decisions?

By researching practical aspects we will be able to highlight issues that need further attention in research and in daily practice. We do not aim to take up a position with regard to approval or disapproval of the various types of EAS, but we may be able to provide practical information that results in new insights into the ethical and legal debate concerning approval or disapproval.

As an Introduction to these issues, I will first discuss the legal regulations concerning EAS in general. Then I will discuss two cases in which physicians who had performed EAS were prosecuted, and the consequences of these cases for the EAS regulations. Furthermore, the different types of advance directives will be discussed, and the debate on the validity of advance directives in cases of dementia will be summarized. Finally, an overview will be given of the research methods that have been applied and the research questions that I aim to answer per chapter in this thesis.

1.2 LEGAL REGULATIONS

The first unofficial procedure for the regulation of EAS started in 1991, and this procedure became official in 1994. However, EAS was then still illegal, but physicians could expect to be exempt from prosecution if they followed several rules that were derived from case law, the so-called 'requirements of due care', and reported the case to the Public Prosecutor. After this procedure was evaluated in 1996, it was amended in 1998, with the establishment of five Regional Review Committees, which took over the initial review of the cases from the Public Prosecutor. These Review Committees advised the Assembly of Prosecutors General whether or not the requirements of due care were met. The current (new) euthanasia legislation came into force in 2002 (Termination of Life on Request and Assisted Suicide Act, 2002). In this new law EAS still falls under the Penal Code, but is no longer illegal if the requirements of due care are met. The Review Committees that were established in 1998 had their control extended and almost all of the requirements of due care were maintained. The requirements as stipulated in the current law are as follows:

a) the physician was convinced that the patient's request for euthanasia was voluntary and well-considered;
b) the physician was convinced that the patient's suffering was unbearable and hopeless;
c) the physician informed the patient about his/her situation and prospects;
d) the physician and the patient were both convinced that there was no other reasonable solution;
e) the physician consulted at least one other, independent physician, who saw the patient and made a written report on the requirements of due care listed in a. to d. above;
f) the physician terminated the patient's life or provided assistance with suicide with due medical care and attention.

These requirements provide legal security for physicians: if a physician has performed EAS according to these requirements, and has subsequently reported it to the Coroner, the EAS is justified by the law, and the physician cannot be punished. Nevertheless, they are inevitably abstract, and each case will be judged individually. A short explanation of the meaning of each requirement is given in the explanatory memorandum (Explanatory Memorandum 'Termination of Life on Request and Assisted Suicide', 1998–1999). A voluntary request is a request that is made by the patient him or herself, with no pressure or influence from any other people. Well-considered refers to requirements c) and d), i.e. the patient must have insight into his or her disease, the diagnosis, prognosis, and possibilities for treatment. The physician must inform the patient and discuss other reasonable solutions to relieve the suffering. The physician and the patient must go through the decision-making process together. The physician must investigate all possible options within the framework of medical palliative care, and offer these to the patient. According to the explanatory memorandum, the patient is then completely free to refuse all treatment and care, without jeopardizing the legality of EAS. The reasons for requesting EAS may differ, and the concept of 'unbearable and hopeless suffering' can be assessed for the specific circumstances of each individual case.

Circumstances or diseases which do or do not cause suffering were deliberately not specified. Reference is made in the explanatory memorandum to the legal case against psychiatrist Chabot, in which it was stated that the extent of suffering is not determined by the cause of the suffering. (I will discuss this case in more detail on the next page.) Reference is also made to an older case, dating back to 1984, in which the Supreme Court stated that unbearable and hopeless suffering can also be caused by progressive deterioration and the prospect of not being able to die in a dignified way. Finally, the explanatory memorandum states that the physician must consult an independent physician —who is not a member of the same practice, a family member, or a subordinate—, must perform the euthanasia or be present at the assisted suicide himself —as opposed to leaving the performance to a nurse or someone else— and must prescribe the correct drugs which have to be administered in a technically and medically correct way.

1.3 LEGAL CASES

It could appear from the above that patients who suffer unbearably and hopelessly, for whom there is no other reasonable solution, and who then request EAS voluntarily and after due deliberation, have a right to EAS. However, patients cannot claim the right to EAS. Physicians have the right to grant requests from patients under these circumstances, but they are never obliged to exercise this right. A physician can refuse to perform EAS for personal reasons, even if a patient's request meets all the legal requirements. The physician does have the legal obligation to refer such a patient to another physician.

Physicians have the right to grant requests for EAS if the requirements of due care are met, but if it is unclear whether the requirements are met in an unprecedented case, the requirements can be further specified by case law. Therefore, physicians will probably be less willing to perform and report such unprecedented cases. Nevertheless, there have been many trials which have contributed to the development of the euthanasia legislation (Weyers, 2002). In such trials the limits of the area which is covered by the euthanasia law have been explored. On the next two pages, I will discuss two cases that are important for this thesis.

Chabot (Dutch Supreme Court, 1994)

About the patient

In 1991, a 50 year-old woman, Mrs. B, was assisted in her suicide by a psychiatrist, Mr. Chabot. Mrs. B was divorced, after an unhappy marriage in which she had been abused. She had two sons from this marriage, the oldest of whom had committed suicide in 1986 at the age of 20. Mrs. B had also considered suicide at that time, but decided that her younger son needed her. By an unfortunate quirk of fate, her second son died of cancer in 1991, also at the age of 20. She had lived for her sons, and before the death of her second son she had already decided that she did not want to continue living after his death. She attempted suicide on the evening of his death with pills from her psychiatrist that she had secretly saved, but failed.

She then looked for someone who would assist her in dying, and after she had been refused several times she met a psychiatrist, Mr. Chabot, and asked him if he would help her. Mr. Chabot agreed to see her, because he thought he could cure her of her death wish. He soon realized that Mrs. B did not want to be treated or cured, and that she was very consistent in her death wish. Mrs. B convinced Mr. Chabot that *for her* her suffering was unbearable and hopeless. Although he did not agree with her death wish, he also thought that she should not be left to die alone. Within two months of starting intensive therapy, he provided her with drugs to commit suicide.

About the court case

In 1994 the Supreme Court found Mr. Chabot 'guilty without imposition of punishment'. The extraordinary thing was that the verdict of guilty was only based on the fact that the consultants had not seen the patient, and not on the absence of a physical illness. The Court assumed that Mrs. B suffered from depression in the strict sense, based on the statement made by Mr. Chabot[b]. With regard to the extent of suffering, the Supreme Court stated that the extent of the suffering has to be abstracted from the cause of the suffering, insofar as the cause of the suffering does not reduce the extent to which the suffering is experienced. Extra caution is required in cases in which the suffering is not caused by a somatic disease, because it is more difficult to determine the severity and hopelessness of the suffering. However, it is possible for a patient to suffer unbearably and hopelessly in spite of the fact that there is no somatic cause of the suffering, or the fact that the patient is not in a terminal phase.

[b] After the court case Mr. Chabot stated in an interview that, in his opinion, Mrs. B suffered from grief rather than from depression in the psychiatric sense or any other psychiatric illness (Klotzko *et al.* 1995).

Brongersma (Dutch Supreme Court, 2002)

About the patient

Mr. Brongersma was quite well-known in the Netherlands, as a former politician, a lawyer, and an active advocate of paedophilia. In 1991, when Mr. Drion proposed the legalization of a 'suicide pill' (which I will discuss later), Mr. Brongersma corresponded with him and said that he was also a proponent of such a pill. In 1993 he first requested his general practitioner (GP) to provide him with a suicide pill, but was refused. In 1996 he first attempted to commit suicide without the help of his GP, but failed. Then, in 1998, he requested his GP to assist him with suicide. At the age of 86 he had become very lonely, and although his physical condition was no worse than that of other people of his age, he regarded this condition as unacceptable and did not want to deteriorate further.

Allegedly, Mr. Brongersma also suffered from the declining acceptance of paedophilia in the Netherlands, but this was denied by the GP's attorney (van Ree, 2001; NRC Handelsblad, 2000). The GP had several conversations with Mr. Brongersma about his death wish, and consulted another GP and a psychiatrist. They all concluded that Mr. Brongersma did not suffer from a psychiatric disease, and was therefore competent to decide about his own life. The GP was convinced that the requirements of due care were met, and assisted Mr. Brongersma with suicide in 1998.

About the court case

This was a first case of EAS in the absence of a severe physical or psychiatric disease to appear before a Court. Although in the first instance the GP was acquitted, on appeal and before the Supreme Court, the GP was found guilty, without imposition of punishment. The Supreme Court stated that the euthanasia legislation was never intended to be applied in cases concerning people who do not have a medically classifiable physical or psychiatric disease (such as is the case with people who are 'tired of living'). Such requests do not fall within the medical domain, and therefore physicians are not qualified to judge such requests.

Implications of these trials

The verdict in the Chabot case would appear to imply that EAS is allowed in the absence of a severe disease. However, in the case against Mr. Brongersma's GP, the Supreme Court stated that the statement that 'the extent of the suffering is not determined by the cause of the suffering', should only be understood in the medical context of Mrs. B's depression.

The verdict in the Brongersma trial gave new impulse to a related debate, concerning the 'Drion Pill'. This pill does not in fact exist, but is a hypothetical suicide pill, named after Mr. Drion, an Emeritus Professor of civil law and former vice-president of the Supreme Court, who first made a plea for such a pill in 1991. According to Drion, older people would be reassured if they had such a pill, knowing that they could end their life if they wished to do so (Drion, 1991). In 2001, Mrs. Borst-Eilers, who was then Minister of Public Health, stated that she would "not be against" the availability of a suicide pill for very old people who are 'through with life'. Furthermore, she said that she did not think that being 'tired of living' was a matter that could be judged by physicians or regulated in EAS legislation (Oostveen, 2001). The Dutch Association for Voluntary Euthanasia (NVVE) actively advocates a suicide pill, and has renamed such a pill 'the last will pill'.

1.4 ADVANCE DIRECTIVES [c]

When a patient becomes incompetent it may be difficult for relatives and physicians to make end-of-life decisions when they are not sure what the patient would have wanted. Such a situation of uncertainty can be prevented if people think in advance about their preferences for treatment at the end of life, and make these preferences known to their relatives and their physician. This may make the decision-making easier and more in accordance with the patient's wishes. There are several types of advance directives that people can formulate:

- **Negative advance directive**
  This advance directive specifies which types of treatment are *not* to be applied. It is possible to specify the circumstances in which they should or should not be applied, such as the chance of improvement. It is possible to refuse all life-prolonging treatment, or it is possible to describe very specific types of treatment that should not be applied, such as resuscitation, artificial nutrition, or blood transfusion. Such negative advance directives must be followed by the carers and physicians, unless there are well-founded reasons not to do so (Medical Treatment Contract Act, 1995).
- **Positive advance directive**
  This advance directive describes treatment, care, etc. that should be applied, e.g. that all treatment options should be attempted even if there is no realistic chance of improvement, or a request for euthanasia under certain circumstances. Carers and physicians are not obliged to follow positive advance directives.
- **Appointing a representative**
  This is an advance directive in which another person is appointed to represent the patient in case of incompetence. The decisions made by this representative have to be followed by physicians and other carers, as long as they are not contrary to the standards of due care.

Incompetence

People can become unable to express their wishes in many ways. Over 20% of the people who die of cancer become fully unconscious before their death (Georges *et al.* 2005), and 44% of the people who die in a nursing home are unconscious in the last 24 hours before their death (Brandt *et al.* submitted). Some people become comatose after an accident. Another cause of incompetence is dementia, and in such cases the validity of advance directives has been strongly debated. I will describe below several arguments that have been used in this debate, which usually concerns the validity of refusing life-prolonging treatment.

[c] The term 'advance directives' used in this thesis refers to correctly used 'conditional' advance directives, and not to written records of present wishes. A physician can ask a patient to write down a verbally expressed wish, if the requested act is potentially illegal in the absence of a request. This can occur in cases of treatment refusal or in cases of EAS. In cases of treatment refusal such a record is legally required, in cases of EAS it is not, but it can give the physician extra assurance that the patient is sure about his request, and it gives the physician proof that he has acted according to the patient's request. In such cases of recording wishes for legal security, it is best if a patient writes down in his/her own words what his/her preferences are in his or her present situation, but often 'conditional' advance directives are used. This is an improper use of such directives, as they are intended for wishes formulated in advance, for situations that have not yet occurred, and are to be used only if that situation occurs and the patient has become unable to express his or her wishes.

Perspectives on negative advance directives in cases of dementia

An important argument in this debate in favor of the use of advance directives is the right to self-determination, according to the principle of autonomy (Dworkin, 1993). Disregarding a directive is considered to be a paternalistic 'third party perspective', leading to distrust of physicians. A counter-argument is that advance directives were formulated at a time when the exact situation in which they would be used was not known, and therefore it is not sure that the patient would really want what is specified in the directive if (s)he would have known what the situation would be (Crippen *et al.* 2000; Berghmans, 2000). Another counter-argument is that the demented person becomes a psychologically different person, and therefore the directives are no longer valid, because the previously competent person does not exist anymore and therefore does not have the right to decide about the currently demented person (Dresser and Robertson, 1989; Dresser, 1995; Robertson, 1991). This is especially debatable if following the directive would shorten the life of a patient who appears to be 'pleasantly demented' (Kuhse, 1999; Firlick, 1991).

This 'different person view' has been countered by the argument that the demented person *is* the same person as the previously competent person, according to the 'narrative view', describing a consistent life story as an important value in defining identity (Rich, 1998; Quante, 1999). Another argument against the different person view is somewhat contradictive of the previous arguments, claiming that self-determination is distorted, not because the patient has become a different person, but because the patient is not a person anymore, since one of the defining characteristics of a person is the ability to see oneself as existing over time. All sentient beings have 'experiential interests', but only persons can anticipate and have desires about their own future. Thereby it is acceptable to comply with the directives of the previously competent person, even if this means that life-prolonging treatment is foregone (Kuhse, 1999). This last argument, in particular, is controversial, going so far as to challenge the sanctity of a life view.

In this theoretical debate, arguments in favor of compliance with advance directives have prevailed, autonomy and self-determination being the main arguments (Berghmans, 1997).

The cautiousness surrounding this debate can be explained by the fact that if the outcome is that advance directives are valid in cases of dementia, negative advance directives must always be followed, and even proponents of the use of advance directives often recognize the greater complexity of the application of directives in practice (Kuhse, 1999). This is especially so if the directive was formulated a long time beforehand, and the intention of the directive is ambiguous (Hertogh and Deerenberg-Kessler, 1995).

If advance directives are considered to be valid in cases of dementia, then *positive* advance directives are also valid. This would seem to be a less controversial conclusion, because the physician is never obliged to follow a positive advance directive. However, in the case of advance directives concerning euthanasia, there are other reasons to question their acceptability. This issue can be approached from two different angles: ethical (should it ever be allowed) and practical (is it ever allowed according to current legislation and the standpoints of the relevant organizations). This Introduction will be restricted to a discussion of the practical aspects.

Advance euthanasia directives

The new 2002 euthanasia legislation of explicitly deals with advance euthanasia directives (Termination of Life on Request and Assisted Suicide Act, 2002). Article 2.1 of this law stipulates the requirements of due care described at the beginning of this Introduction. Article 2.2 concerns patients who are no longer capable of expressing their own wishes. According to this Article, physicians are allowed to perform euthanasia for such patients, based on a written request that was made at the time when they were still competent, provided that the requirements of due care, as stipulated in Article 2.1, are met. This implies that the requirement of 'unbearable suffering' has to be met. This is normally considered to be a subjective patient experience. Comatose patients are considered to be incapable of such an experience (Payne *et al.* 1996). Article 2.2, focussing on

incompetent patients who were previously competent, therefore appears to apply, in particular, to patients with dementia. Whether or not these patients can suffer unbearably was already a subject of debate before this new law was first proposed in 1998. The Royal Dutch Medical Association (RDMA) was the first organization to take an official standpoint in 1997 (Royal Dutch Medical Association, 1997). In its opinion, a demented patient who has serious symptoms, indicating serious suffering, can suffer unbearably and hopelessly just like a non-demented patient, and the fact that the patient is demented is important but only secondary information. This also applies, and in particular, if the serious suffering is a consequence of foregoing treatment, as requested in the advance directive of the patient. The question of whether or not the requirements of due care could also be met in the absence of suffering in addition to the dementia, was left unanswered by the RDMA. The Dutch Health Council published a similar standpoint in 2002 (Health Council of the Netherlands, 2002). The Dutch Association of Nursing Home Physicians (NVVA) also published a standpoint concerning this subject in 1997, which they intended to be a more detailed guide for practical use (Dutch Association of Nursing Home Physicians, 1997). Their standpoint is that the advance euthanasia directives of patients in the advanced stages of dementia should never be complied with, because these patients can never have enough understanding of their situation to meet the requirement of unbearable suffering. However, the NVVA does not exclude all cases of physician-assisted death. In very rare instances, when additional illnesses or complications cannot be satisfactorily treated, and the physician is of the opinion that the patient is in an unacceptable state of suffering as a consequence, the NVVA states that physician-assisted death can be ethically acceptable, and advance directives can serve to support the decision-making.

No cases of euthanasia based on an advance directive of an incompetent patient have yet been reported to the Regional Review Committees. (personal communication, 30-7-2004)

1.5 OUTLINE OF THIS THESIS

This thesis is divided into four parts. After this Introduction (Part 1) to the general concepts of EAS and the current regulations from the perspective of the themes of this thesis, Part 2 consists of three chapters which address several issues that are related to being weary of life, and Part 3 consists of three chapters concerning advance directives, followed by a General Discussion in Part 4. Each of the chapters in Part 2 and 3 can also be read independently.

I will now describe the research methods used in this thesis and the research questions I aim to answer in the various chapters. The research questions were already introduced briefly at the beginning of this part: there is much debate on the issues of EAS in the absence of a severe disease and EAS in cases of advanced dementia, but this debate is largely theoretical. There appears to be much public support for EAS in such cases, especially in cases of advanced dementia, but little or nothing is known about the representativeness of these opinions for the general population or the physicians in the Netherlands. More importantly, nothing is known about how often these cases occur in practice. The fact that no such cases have been reported to the Review Committees, does not mean that these cases do not occur, because only about half of the cases of EAS are reported (van der Wal *et al.* 2003). The aim of this thesis is to investigate the practice of EAS in the absence of a severe disease and in cases of advanced dementia, and to provide information to advance the ongoing debate. For this purpose, not only the occurrence of (requests for) EAS in such cases will be investigated, but also several closely related issues, such as being tired of living, a suicide pill, and the prevalence of advance directives. Through interviews with physicians, insight is obtained with regard to how often requests are made in the absence of a severe disease and in cases of dementia (by means of an advance directive), and the experiences of the physicians in such cases. Furthermore, data on the attitudes of physicians and the general population in the Netherlands towards these issues is also presented. In the last part of this thesis, an analysis will be made of EAS in the absence of a severe disease and in cases of advanced dementia, highlighting points that need further attention in the

debate, in research and in practice. Below, I will give a brief description of the research methods that were applied and the research questions to be answered in each chapter.

Methods

This thesis was originally based on a study that was part of a large-scale study to evaluate the review procedure for EAS (1a,b,c). However, the present thesis was enriched with data from other studies concerning similar subjects (2,3,4). Further information on the methods is provided in the separate chapters.

1) *Evaluation of the review procedure for EAS*
   a) *Physician interviews (Chapters 2, 4, 6):* A random sample of GPs (*n*=125), nursing home physicians (*n*=77), and clinical specialists (cardiologists, surgeons and specialists in internal medicine, pulmonology and neurology) (*n*=208) were interviewed in 2002. They were retrospectively interviewed by trained physicians about their experiences with requests for EAS from older people who did not have a severe disease and with demented patients with an advance euthanasia directive. Of the 482 physicians who were selected for this study, 72 were unwilling to participate (15%), mostly due to a lack of time.
   b) *General population questionnaires (Chapters 4, 5):* 1,379 people in the general population completed a questionnaire in September 2002. These people were participants in an existing consumer panel selected by the NIVEL (Netherlands Institute for Health Services Research), as representative of the population in the Netherlands above the age of 18 years. The response was 78%.
   c) *Interviews with relatives (Chapters 4, 5*): 87 relatives of patients who had died after EAS were interviewed in 2002. The relatives were selected through a sample of 167 physicians who had reported EAS to a Regional Review Committee in 2001 or 2002. These physicians were asked to contact the relative who had been most involved in caring for the patient, and to ask them if they would be willing to be interviewed about their experiences and attitudes. Of the 97 relatives (58%) who were contacted, 87 relatives (90%) agreed to be interviewed.
2) *SCEN GP questionnaires (Chapter 3):* The data presented in Chapter 3 of this thesis were derived from a study that was designed to evaluate the project 'Support and Consultation on Euthanasia in the Netherlands' (SCEN), which is a network of specifically trained physicians from whom GPs can obtain information or request consultation. For the evaluation of this project it was necessary to collect data before and after the implementation of SCEN. This resulted in 1,227 completed questionnaires in the 'pre-test'(response 70%) in 2000/2001, and 3,615 completed questionnaires in the 'post-test' (response 60%) in 2001/2002. The part of the questionnaires that is relevant for this thesis is that in which the GPs were asked to describe their most recent case in which a patient had requested EAS. Because the implementation of SCEN is not relevant for this thesis, the requests described in the pre-test were added to those described in the post-test. A selection was made of patients for whom 'being tired of living' played a major role in their request for EAS.
3) *LASA interviews with older people (Chapter 5):* The data concerning older people were derived from the 'Longitudinal Aging Study Amsterdam' (LASA). The subjects in this study are interviewed every three years. Chapter 5 is based on interviews in '98–'99 with 1874 people between 61 and 92 years of age, because in that year more extensive questions were asked about end-of-life preferences.

4) *Artificial nutrition and hydration questionnaires (physicians, nurses and relatives) (Chapter 7):* The data were derived from a study investigating artificial nutrition and hydration in nursing home patients with dementia, in which questionnaires were completed by 107 physicians, 148 nurses and 136 relatives of the patients for whom a decision concerning artificial nutrition and hydration was made. For Chapter 7 we used data from the responses to 15 statements about artificial nutrition and hydration, advance directives, hastening death, self-determination and euthanasia, and nursing home policy.

Aims and research questions

Weary of life (Part 2)

Chapter 2 Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: an interview study

The aim is to estimate the incidence of requests for EAS in the absence of a severe disease, to obtain insight into the characteristics of the patients and the reasons why they make such requests, and to learn more about how physicians, and in particular GPs, deal with such requests.

Chapter 3 When being 'tired of living' plays an important role in a request for euthanasia or physician-assisted suicide: patient characteristics and the physician's decision

The aim is to answer the following research questions: To what extent does being tired of living, as a reason for requesting EAS, occur in the presence or absence of a severe disease? What are the characteristics and symptoms of patients who request EAS because they are tired of living? Do physicians grant requests from patients who are tired of living and, if so, in what cases?

Chapter 4 A 'suicide pill' for older people: attitudes of physicians, the general population and relatives of patients who died after euthanasia or physician-assisted suicide in the Netherlands

The aim is to describe the attitudes and opinions of physicians, the general population and relatives of patients who died after EAS, with regard to EAS in the absence of a severe disease, and the availability of a 'suicide pill' for older people. Furthermore, to obtain insight into the attitudes of these three groups of people, to compare their attitudes, and to analyze the determinants of their attitudes.

Advance directives (Part 3)

Chapter 5 Frequency and determinants of advance directives concerning end-of-life care

The aim is to study the prevalence of advance directives in three different groups: people over 60 years of age, people up to 60 years of age, and relatives of patients who had died after EAS. Furthermore, to determine which factors are associated with the formulation of an advance directive, especially in the group of people over 60 years of age. The associated factors are arranged according to the three following components: predisposing factors (e.g. age, gender), enabling factors (e.g. education) and need factors (health-related factors).

Chapter 6 Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands

The aim is to estimate the incidence of (compliance with) advance euthanasia directives of demented patients in the Netherlands, to gain knowledge about the experiences of physicians, and to obtain insight into the opinion of physicians concerning the applicability of advance euthanasia directives of demented patients, and the extent of suffering of demented patients.

Chapter 7 Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia

The aim is to investigate and compare the attitudes of physicians, nurses and relatives towards medical end-of-life decisions concerning patients with dementia and to determine the factors that could influence attitude towards these issues.

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Part 2
Weary of life

Chapter 2

Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: an interview study

"It makes a great deal of difference whether a man is lengthening his life or his death. But if the body is useless for service, why should one not free the struggling soul? Perhaps one ought to do this a little before the debt is due, lest, when it falls due, he may be unable to perform the act."

Seneca

ABSTRACT

Objective : To determine how often requests are made for euthanasia and physician-assisted suicide (EAS) in the absence of severe disease and how such requests are dealt with in medical practice in the Netherlands.

Methods : Retrospective interview study. Participants: 125 general practitioners (GPs), 77 nursing home physicians (NHPs), and 208 clinical specialists.

Results : In the Netherlands, each year approximately 400 people request EAS, because they are 'weary of life'. Thirty percent of all physicians have at some time received an explicit request for EAS in the absence of severe disease; 3% of all physicians had granted a request for EAS in such a case.
Most requests for EAS to GPs in the absence of severe disease (*n*=29) were made by single people aged 80 and over. While their problems were most frequently of a social nature, 79% had one or more non-severe illnesses. Most GPs refused the request; half of them proposed an alternative treatment, which the patient often refused. Nineteen people who did not receive any treatment persisted in their wish to die; the request for EAS from 5 out of 10 patients who received one or more types of treatment was withdrawn or became less explicit.

Conclusions : Most physicians in the Netherlands refuse requests for EAS in the absence of severe disease. Most patients persist in their request. In an aging population more research is needed to provide physicians with practical interventions to prevent suicide and to make life bearable and satisfactory for elderly people who wish to die.

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Life expectancy is increasing in industrialized countries, and in most Western countries 50% of the population can already expect to survive to the age of 80 years (Kinsella, 1996). Old age is often accompanied by disabilities and a reduced quality of life. Some elderly people consider this to be unacceptable and develop a wish to die. There are several factors associated with increasing age that are also associated with a wish to die, such as depression, not being married, poor self-rated health, disability, pain, hearing impairment, visual impairment and living in a nursing home (Jorm *et al.* 1995).

Whereas most people will think suicide too drastic a measure, their only alternative is to wait until time fulfills their wish to die. In the Netherlands, however, where there is increasing openness about requesting assistance with dying from a physician, elderly people may consider this a third option. This has resulted in a debate about the ethics of euthanasia and physician-assisted suicide (EAS) for elderly people who wish to die but do not suffer from a severe physical or psychiatric disease. This debate has been further stimulated by a test case in the Netherlands: a general practitioner (GP) who assisted an elderly and ailing, but not severely ill, patient to commit suicide was prosecuted (see 'Case Brongersma' in the Introduction). The GP thought he had met the requirements for prudent practice: a well-considered voluntary request for EAS of the patient, unbearable and hopeless suffering, no treatment alternatives, consulting another physician, and reporting the case to the authorities. In first instance the physician was acquitted, but on appeal and before the Supreme Court he was found guilty without imposition of a punishment. An important argument in the verdict of the Supreme Court was that dealing with a wish to die in the absence of a severe disease does not fall within the medical domain of a physician. The physician should have consulted an expert, although it remained unclear who should be considered an expert in this field (Dutch Supreme Court, 2003).

We performed this study several months before the verdict of the Supreme Court was announced. The aim was to estimate the incidence of requests for EAS in the absence of a severe disease, to get a general insight in the characteristics and reasons of the patients who make such requests, and to learn more about how physicians, and in particular GPs, deal with such requests.

METHODS

Definitions

Euthanasia is defined as the administration of drugs with the explicit intention of ending the patient's life at his/her explicit request. Physician-assisted suicide is defined as the prescription or supply of drugs with the explicit intention to enable the patient to end his/her own life.

Design and study population

This study was performed in 2002 as part of a large-scale study of medical decision-making at the end of life, commissioned by the Minister of Health, Welfare and Sports and the Minister of Justice, and consisted of retrospective semi-structured interviews with a random sample of nursing home physicians (NHPs) (n=77), GPs (n=125) and clinical specialists (cardiologists, surgeons and specialists in internal medicine, pulmonology and neurology) (n=208) (Onwuteaka-Philipsen *et al.* 2003; van der Wal *et al.* 2003). To meet the criteria for inclusion in this study, these physicians had to be practicing in their registered specialty in the same nursing home, practice or hospital for the past 2 years. Of the 482 physicians who met the selection criteria, 72 were unwilling to participate (15%), mostly due to a lack of time.

Measuring instruments and analysis

To enable the physicians to feel free to speak about potentially illegal acts, anonymity was guaranteed by the researchers. Moreover, the Ministry of Justice guaranteed that it would not initiate any judicial inquiries based on the information collected in this study.

The interviews were conducted by physicians who had received specific training for this study.

The interviews had an average duration of 1½–2 hours. Clinical specialists, NHPs and GPs were asked about the main reasons for the requests for EAS that they had

received: a physical disease, a psychiatric disease or being 'weary of life'. Physicians knew before the interview what the subject of the interview would be, and they were asked to make an overview of the frequencies of requests for EAS they had received. This method was chosen to make estimates of the number of requests for EAS in the Netherlands. Furthermore, GPs and NHPs were asked about most recent requests for EAS in the absence of a severe disease. The interviewers explained our definition of this to the respondent as follows: "It does occur that patients do not want to continue living, whereas they do not have a severe physical or psychiatric disease. Sometimes this is referred to as suffering from life, being through with life or being tired of living. It is possible that the patient has health problems —e.g. a chronic illness or ailments of old age— it is also possible that the patient is healthy." After this explanation the interviewer asked whether it had ever occurred that a patient who did not suffer from a physical or psychiatric disease had explicitly requested the respondent for EAS. In case of doubt about the definition of 'severe disease', the interviewer had more extensive information, e.g. someone with a clinical depression was considered to have a severe illness, while someone with only depressed symptoms was not. Only GPs were asked to describe a request in detail. GPs were selected because we assumed their patients would more often than the patients of other physicians meet our definition of not having a severe disease. The GPs were asked to describe the most recent case in which a patient requested EAS in the absence of severe disease.

If they had ever granted such a request they were asked to describe the most recently granted request (n=4); if not, they described the most recent request that was not granted (n=28). Of the 28 not granted requests, three were not included in the analysis because the patients appeared to have a severe psychiatric disease.

The interviews consisted mainly of open-ended questions. Most questions did have pre-structured answering categories, but these were not read out to the respondent. These categories were given to the interviewer to bring nuance to answers that could otherwise have been missed by them. For some questions, the answer categories were made visible to the respondent with cards, e.g. with the question about important reasons for the request for EAS, because we wanted to know of each of the reasons derived from previous research whether they played an important role or not. To also develop an understanding of the personal situation of the patient there was also space with each question to describe a more extensive answer. During the interviews, physicians could check medical records of cases they were discussing. Due to the peculiarity of requests for EAS in the absence of severe disease, most physicians remembered these cases in detail.

To calculate estimates that were representative for the Netherlands the numbers of (requests for) EAS were weighted for specialty of the physician and corrected for the 5% of the deaths covered by other physicians than the seven types studied.

RESULTS

Requests: frequencies, patient characteristics and reasons

Table 1 shows the annual number of requests for EAS and the main reasons. Of all the explicit requests that were primarily based on 'physical disease', approximately 42% were granted (approx. 3800 out of 9000). Explicit requests that were primarily based on a 'psychiatric disease' were never granted, and explicit requests based on being 'weary of life' were almost never granted (approx. 1%).

Thirty percent of the GPs and NHPs had at least once received an explicit request for EAS from a patient who did not suffer from a severe physical or psychiatric disease; 11% had received an explicit request in the past 2 years. Three percent of all GPs had granted such a request, but not in the past 2 years. None of the NHPs had ever granted such a request (data not shown).

Table 1 Number of patients who explicitly requested euthanasia or physician-assisted suicide (EAS) in 2000 and 2001 and estimated annual number in the Netherlands, according to specialty and to the main reason for the request: a physical disease, a psychiatric disease or being weary of life

	General Practitioners (*n*=125)	Clinical Specialists (*n*=208)*	Nursing Home Physicians (*n*=77)	Total (95% CI) (*n*=410)*
Respondents: no. of patients who requested EAS in 2000 and 2001	227	327	81	635
Main reason for the request†:				
Physical disease	91.2%	97.4%	81.0%	92.6%
Psychiatric disease	3.5%	0.9%	7.5%	2.9%
Weary of life	5.3%	1.7%	11.4%	4.5%
The Netherlands: estimated annual no. of patients who request EAS‡	6375	2900	425	9700 (8800—10500)
Main reason for the request:				
Physical disease	5800	2825	350	9000 (8125—9875)
Psychiatric disease	225	25	25	275 (125—450)
Weary of life	325	50	50	425 (225—650)

* One missing case.
† The percentages for clinical specialists and the total are weighted for specialty of the physician.
‡ The estimates for the Netherlands were weighted and rounded.

The average age of the patients at the time of their first request was 81 years (Table 2). None of the patients had a severe disease, but 79% had one or more non-severe illnesses, such as stable status after cancer or a heart condition (11), visual or hearing impairment (7/5), decreased mobility (5), arthritis (3), and intestinal disorders (3). In spite of this, the physicians described their health status most frequently as reasonable, and their problems were more often of a social or mental nature. In 72% of the cases the physician stated that the patient was receiving adequate care.

The reasons for the requests for EAS were being through with life (55%), physical decline (55%) and being tired of living (48%) (Table 3).

Table 2 Characteristics of patients who made a request to their general practitioner for euthanasia or physician-assisted suicide (EAS) in the absence of a severe disease (*n*=29)*

	n	%		*n*	%
Age at first request (years)			**Problems†,‡**		
60—69	3	10	**physical**	6	22
70—79	9	31	(lack of appetite 7, sleeping disorder 6, pain 2)		
80—89	11	38	**communicative**	6	22
90—97	6	21	(blind 7, deaf 5, unable to write 5)		
Gender			**mobility**	6	22
male	13	45	(tiredness 9, dependent for ADL 7, unable to walk 5)		
female	16	55	**mental**	11	41
Partner			(melancholy 12, unable to cope 11, depressed 10)		
yes	7	24	**societal**	16	59
no	22	76	(lack of (leisure)activities 19, no valuable role in life 15, lack of social network 12)		
Children					
good contact	12	41	**One or more non-severe illnesses**		
low quality/no contact	7	24	yes	23	79
unknown contact	2	7	no	6	21
no children	7	24	**Care evaluation**		
unknown	1	3	adequate	21	72
Health status			inadequate	7	24
good	9	31	unknown	1	3
reasonable	14	48	**Ever attempted suicide**		
moderate	5	17	yes	1	3
poor	1	3	no	27	93
Under care of this GP for			unknown	1	3
<1 year	1	3	**Competent to overlook own situation and**		
1—5 years	5	17	**adequately make decisions about it†**		
>5 years	23	79	yes	21	78
Personality traits			not fully	6	22
taken stock of life	25	86	**Received care†**		
intellectual/educated	21	72	umbrella care	15	56
become isolated	17	59	housekeeping	12	44
difficulty with dependence	17	59	residential home	7	26
proud of own achievements in life	16	55	district nursing care	4	15
difficulty with adjusting to old age	16	55	spiritual care	3	11
hopeless and despondent	13	45	voluntary services	3	11
difficulty with loss of standing	11	38	home care	2	7
difficulty with death of partner	8	28	private nursing	1	4
fear of loss of competence	8	28			
simple-minded	6	21			
financial problems	0	0			

* Requests granted and not granted.

† Two missing cases.

‡ For 33 items in 5 areas the physician assessed on a scale from 1 to 5 the extent of the patient's problems at the time of the first explicit request for EAS. For example, the definition of physical problems was if the patient had considerable problems (score 4 or 5) with 2 or more items in that area. For each area the three items that were most frequently assessed with a score of 4 or 5 are shown, together with the number of patients who scored 4 or 5 on that item. In this way all problems were assessed.

Table 3 Reasons for the request for euthanasia or physician-assisted suicide (EAS) in the absence of a severe disease (*n*=29)*

	All reasons		Most important reason†	
	n	%	*n*	%
Through with life	16	55	9	32
Physical decline	16	55	4	14
Tired of living	14	48	1	4
No purpose in life	12	41	0	0
Melancholy/depressed	11	38	3	11
Loneliness	11	38	2	7
Dependence	9	31	1	4
Suffering from life	8	28	1	4
Deterioration/loss of dignity/loss of status	6	21	1	4
Not wanting to be a burden on family anymore	5	17	0	0
Pain	4	14	2	7
Cognitive decline	4	14	0	0
Death of a relative	3	10	2	7
Unable to live independently	3	10	0	0
Other	4	14	2	7

* Requests granted and not granted. More than one answer was possible.
† One missing case.

Course of action of the physician and course of life of the patient

Physicians refused requests for several reasons: the patient did not suffer unbearably and hopelessly (48%) and the patient did not suffer from a severe disease and/or the suffering of the patient was not part of the medical domain (43%) (data not shown).

In 14 out of 29 cases the physician considered one or more types of treatment (Table 4). Four patients refused all the suggested treatments, three patients refused some of the suggested treatments, but received one or more other treatments.

Ten patients received one or more treatments. After receiving treatment, three of these patients no longer wanted EAS. Of these three patients, one was treated with anti-depressant medication, the second received psycho-social support and the third was hospitalized and treated for shortness of breath, and also received psychiatric and psychosocial support. These patients were persuaded to moderate their request for EAS but they still wanted to be able to end their life in due time if they so wished. In two cases the request was withdrawn completely, in one case this happened after treatment with painkillers and in the other case after treatment of a medical problem in combination with antidepressant medication. The other five patients maintained their explicit request for EAS after they had received treatment. One of these patients went to another physician who granted the request for EAS.

Nineteen patients who did not receive any treatment persisted in their request for EAS and in four cases the request for EAS was granted. five patients took their own life after their request was denied; three hanged themselves and two died of self-starvation, one of them at the advice of the physician. The remaining 10 patients persisted in their request for EAS. At the time of the study four had died of natural causes.

To give an impression of the patients described in this article, a combined description of the characteristics of several patients is given as an example in the following 'Case report'. This description is a combination of the characteristics of several patients.

Table 4 Treatments considered and provided by the GP and whether the request for euthanasia or physician-assisted suicide (EAS) was withdrawn or became less explicit in time (*n*=29)*

Treatment	Treatment considered by the physician†	Treatment provided	Request was withdrawn or became less explicit in time
No	15‡	19‡	0
Yes	14	10	5
anti-depressant medication	5	4	2
psychiatric/psychological††	6	2	1
psychosocial††	7	3	2
analgesic medication	2	2	1
other medical	4	3	2

* Requests granted and not granted.
† Possible treatment considered by the physician after the explicit request for EAS, that was not provided before the request.
‡ Four patients refused all treatment, so in 15 cases no treatment was considered and in 19 cases no treatment was provided.
†† psychiatric/psychological treatment= treatment by a psychiatrist or a psychologist, psychosocial treatment= all other types of psychological or social support by the GP, social services, volunteers, etc.

Case report

A woman, 81 years old, asked her GP if he had a pill for her to end her life. The GP had known her for a long time and the question did not really surprise him. Since her husband died 15 years ago, she had lived alone. Since then, people around her had died and she was the last one of her generation alive in her family. She had good relationships with her three sons, even though she often complained that they did not spend enough time with her. She had a visual and a hearing impairment and she had difficulty walking, but she was well taken care of in sheltered accommodation. When her GP asked her why she wanted to end her life, she said that she was weary of life. She felt that she was physically declining and she did not want to live to see how she deteriorated further. She had seen members of her family developing dementia and she did not want that to happen to her. She had no prospects and felt lonely most of the time. She had drawn up the balance and decided that she was better off dead. When her GP explained why he could not provide a pill she seemed to accept the situation. After that they had several conversations concerning the subject. She seemed to accept her predicament, but she said regularly that she would rather be dead and that she hoped her GP would change his mind.

More detailed descriptions of similar patients have recently been published (De Burlet and Hazenberg, 2003; Calman, 2004).

DISCUSSION

One limitation of this study is that it is a retrospective interview study. Therefore some doubts may arise with regard to validity, even though the physicians remembered these patients very well, probably due to the peculiarity of the requests for EAS, which were from older people who did not have a severe disease. Another limitation of this study is that only physicians were interviewed. To obtain a complete picture of the reasons involved and the line of thought of patients leading to their wish to die, they too should be included in a study. Furthermore, only a small number of cases have been described in detail in the interviews, due to the fact that such requests are a rare occurrence. However, we think that because of the high response rate and the guaranteed anonymity, this study provides the initial reliable insight into requests for EAS in the absence of a severe disease. Interviewing people with a wish to die might be a logical next step in further research.

It is estimated that each year 400 people in the Netherlands request EAS because they are 'weary of life'. These people mainly suffer from the physical ailments and social

problems that are frequently encountered in older age. They seem to have a crude but rational deliberation: after a long life they are now deteriorating physically and they feel that they have no role left in life. The question remains, however, as to why they want to actively intervene instead of waiting for time to do its work. It seems that circumstances such as the loss of a partner, increasing isolation due to the death of people around them, and physical ailments can make everyday life such a negative experience that it can turn being weary of life into a reason to actively wish to die.

It could be said that all the patients in our study suffered from *depressive symptoms*, since they all had a wish to die. In the Netherlands it is widely accepted that it is possible for a person to have a death wish without suffering from a *clinical depression*. Of course, especially in other countries, not everybody agrees with this. We cannot rule out the possibility that some of the patients in our study did suffer from a clinical depression, even though this was not diagnosed by the participating physicians. We realize that differentiation between depressive symptoms and a clinical depression is rather complicated, especially in older people, and that a clinical depression is often not detected by physicians. However, there is probably a much smaller chance of missing such a diagnosis in a patient who makes an explicit request for EAS. In the first place, because the wish to die is made explicit by the patient and can therefore not be overlooked, and also because it is a normal procedure when dealing with requests for EAS to exclude the possibility of a depression, because the competency of a patient with a depression can be doubted, and treatment may be possible.

Most physicians in the Netherlands refuse requests for EAS in the absence of a severe disease, mainly because they do not consider these patients to be suffering unbearably or hopelessly. Requests that had been granted had all been granted longer than 2 years ago, so we have found no evidence of a 'slippery slope' of EAS widening its scope in practice to patients who are not severely ill, even though the existence of a debate about EAS for patients who are not severely ill might, in itself, be considered to be an indication of a slippery slope.

Physicians apparently do not always consider a request for EAS as an opportunity to suggest certain treatment or other interventions that could make life more bearable or satisfactory for these patients. Another study also showed that physicians had difficulty addressing patients' existential suffering (Kohlwes *et al.* 2001). The responsibility and expertise of a physician in treating these patients is debatable, since it can be questioned to what extent the problems of these patients pertain to the medical domain (Smith, 2001; Leibovici and Lievre, 2002). The Royal Dutch Medical Association has established a committee that addresses this question. However, whether or not these problems pertain to the medical domain, these patients turn to a physician to ask for help.

Little is known about the possibilities for treatment for these patients: can they be helped, in what way, and by whom? While much has been published concerning suicide in the elderly, studies about death wishes are virtually non-existent. This is remarkable, since 9.5% of people aged 65 years and over reported death and/or suicidal ideation or intention in the past year, while only 0.14% had actually attempted suicide (Scocco and De Leo, 2002).

However, the fact that so little is known about the possibility of treating people who have a wish to die, does not dismiss them as being patients who cannot be treated at all by a physician. In two thirds of the cases in this study the physicians did not treat the patient and in half of the cases treatment was not even considered. Should this be seen as unwarranted 'therapeutic nihilism', or is there really nothing that a physician can do in such situations? The fact is, that in this study the request was withdrawn or became less explicit after treatment in 5 cases, but this never happened when no treatment was given. Although the problems of these patients may seem to be inevitable, because they are inherent to aging and determined by societal values, the significance of physical discomforts should not be underestimated as a reason underlying a wish to die. Interventions mitigated some of the problems, such as pain, visual and hearing impairment, individual physical discomforts and depression, support in taking up activities and social contacts was also helpful in some cases. Maybe not all of these aspects of treatment seem typical of

the responsibilities of a physician, but at least observing the necessity of treatment and referral certainly are.
In our opinion, however small the odds of recovery appear to be, treatment should always be considered. Therefore research is needed into practical approaches for physicians, not only to prevent suicide, but also to make life more bearable and satisfactory for elderly people who wish to die.

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Chapter 3

When being ‘tired of living’ plays an important role in a request for euthanasia or physician-assisted suicide: patient characteristics and the physician’s decision

“The World Health Organization’s famous definition of health as ‘complete physical, psychological and social well-being’ is achieved only at the point of simultaneous orgasm, leaving most of us unhealthy most of the time.”

Imre Loeffler

ABSTRACT

Background : In the Netherlands physicians are allowed to grant requests for euthanasia or physician-assisted suicide (EAS) if they meet several requirements of due care. According to case law, a physician is not allowed to end the life of a patient whose request for EAS is based on being 'tired of living', because such a request falls outside the medical domain. Our previous studies have shown that in spite of this, such requests are made approximately 400 times a year.

Objectives : To learn more about patients who request EAS because they are tired of living, and about factors that influence the decision of the physician.

Methods : Questionnaires (*n*=4,842) completed by general practitioners (*n*=3,994).

Results : According to the physicians, 17% of patients who requested EAS were 'tired of living'. Of 139 patients in whose request for EAS being tired of living played a major role, 47% suffered from cancer, 25% suffered from another severe disease and 28% had no severe disease. In all three groups the same three symptoms occurred most frequently, 'feeling bad', 'tired', and 'not active'. Each of these symptoms occurred in more than half of the patients in each group. Most of the requests from patients with cancer were granted, but those from patients who had some other severe disease, or no severe disease at all, were refused. Factors that were related to granting a request were: the presence of unbearable and hopeless suffering, the absence of alternatives, and the absence of depressive symptoms.

Conclusions : Being tired of living can play a major role in requests for EAS, both in the absence and the presence of a severe disease. The high occurrence of symptoms in the absence of a classifiable severe disease implies that physical symptoms are prevalent in this group of patients, leaving the legal requirement for EAS of 'a medical cause' open to interpretation in the more complex medical practice.

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In the Netherlands physicians are allowed to grant requests for euthanasia or physician-assisted suicide (EAS) if they meet the requirements of due care, which include the patient's request being voluntary and well-considered, the patient's suffering being unbearable and hopeless, and the absence of treatment alternatives. Case law from 1994 states that the extent of the suffering is determined by the way in which it is experienced, and should be abstracted from the cause. However, case law from 2002 adds to this that the cause must be medical: if a patient is suffering from the consequences of old age and requests EAS because (s)he is 'tired of living', but does not suffer from a severe disease, the physician is not allowed to grant such a request (Dutch Supreme Court, 2002). One of the reasons for this, as given by the Supreme Court, is that a physician is a medical expert, and can therefore judge the extent of unbearable and hopeless suffering of a patient with a medically defined disease, but is not an expert in dealing with patients who are tired of living, and therefore cannot judge their suffering or the adequacy of their treatment. Moreover, the law regarding EAS was intended to be applied to patients with a severe physical or psychiatric disease, and not to patients who have ailments due to old age and are tired of living.

Apparently the diagnosis of a particular severe disease and a physician's knowledge of the accompanying clinical picture is considered to be very important in assessing (the extent of) the suffering. However, such an assumption seems to ignore the subjective aspect of the patient's experience of the extent of the suffering. It is known that in most cases the most important reasons for patients to request EAS are not physical symptoms, such as pain, but psychological reasons, such as loss of dignity, deterioration and loss of meaning (van der Wal and van der Maas, 1996; Meier *et al.* 2003).

Our previous studies have shown that in the Netherlands explicit requests for EAS from patients who are 'weary of life' occur about 400 times a year (Rurup *et al.* 2005). In this article we aim to answer the following questions: To what extent does being tired of living, as a reason for requesting EAS, occur in the presence or absence of a severe disease? What are the characteristics and symptoms of patients who request EAS because they are tired of living? And what are their reasons? Do physicians grant requests from patients who are tired of living and, if so, in what cases?

METHODS

Definitions

Euthanasia is defined as the administration of drugs with the explicit intention of ending the patient's life at his/her explicit request. Physician-assisted suicide is defined as the prescription or supply of drugs at the explicit request of the patient with the explicit intention to enable the patient to end his/her own life.

Measurement instruments and study population

The data used in this article are derived from the evaluation study of the project 'Support and Consultation on Euthanasia in the Netherlands' (SCEN) (Onwuteaka-Philipsen *et al.* 2003). SCEN is a network of especially trained physicians from whom general practitioners (GPs) can obtain information and advice, or request a formal consultation (required for the euthanasia notification procedure). For this study all GPs in 18 (out of 23) general practice regions in the Netherlands received a post-test questionnaire approximately 18 months after the start of SCEN in their region (in 2001 and 2002). All GPs in four of these regions had also received a pre-test questionnaire shortly before the start of SCEN.

Both for the pre-test and the post-test, the addresses of all GPs working in these regions were obtained from GP registers. Of the 1,931 GPs who received a pre-test questionnaire, 177 were no longer working in the region, or had retired, or were ill, and 1,227 GPs returned the questionnaire (response 70%). Of the 6,596 GPs who received a post-test questionnaire, 556 were no longer working in the region, or had retired, or were ill, and 3,615 GPs returned the questionnaire (response 60%).

The part of the pre-test and the post-test questionnaire that is relevant for this article is that in which the GPs were asked to describe their most recent case in which a patient

had requested EAS. In the pre-test this applied to requests from January 1998 onwards, and in the post-test this applied to requests that had been made in the past 18 months. In the pre-test such a request was described by 718 GPs, and in the post-test by 1,701 GPs. Because the implementation of SCEN is not relevant in this article, the requests described in the pre-test were added to those described in the post-test.

The gravity of various symptoms was assessed by the physician by means of the questionnaire, on a scale adapted from a scale that was developed for use on a palliative care unit (Bruera *et al.* 1991). The scale ranged from 1–5, with 1 representing the absence of the symptom and 5 representing the symptom in its gravest form. In the analysis, a patient was considered to suffer from a symptom if it had been assessed with a score of 4 or 5 by the physician.

Anonymity

Anonymity was guaranteed by a procedure involving an intermediary. The intermediary assigned a number to each respondent and mailed the questionnaires. The researchers received the numbered and completed questionnaires without knowing the names of the respondents, and sent a list of the numbers on the questionnaires to the intermediary. The intermediary then sent reminders to the physicians who had not returned their questionnaires. In this way, no connection could be made between a physician and the content of a questionnaire by either the intermediary or the researchers.

Analysis

The physicians were asked to state the most important reasons for the patient to request EAS, in order of importance. Most respondents gave multiple reasons. 'Being tired of living' was one of the important reasons for 408 patients. For part of the analysis for this article we wanted to narrow this group down to patients for whom being tired of living played *a major role* in the request, and was more than just one of the important reasons. Therefore, from this group of 408 patients for whom being tired of living was an important reason we selected only those who also met one of the following criteria: (1) *the most* important reason for the request was 'being tired of living' (n=92) or 'being disabled or immobile' (n=19); (2) the main diagnosis according to the physician was 'old age/physical deterioration' (n=37) or 'being through with life' (n=17). These categories were not mutually exclusive. Since physicians who were sent a questionnaire in the pre-test kept the same number in the post-test, we were able to determine that both the pre-test and the post-test questionnaires of two physicians were included in this selection, but they both discussed different cases in the pre-test and post-test. The cases were divided into three categories according to the patient's diagnosis: patients suffering from cancer, patients suffering from a severe disease other than cancer, and patients who were not suffering from a severe disease, except perhaps from old age or physical deterioration (see Fig. 1).

All characteristics of the request that could possibly influence whether or not a physician would grant the request were included, and in a bivariate analysis the odds ratio and 95% confidence interval calculated. All variables that were not dichotomous were dichotomized, by forming groups that were approximately equal in size. All variables were significant (p<0.05) and were used in a multivariate analysis. Stepwise backward logistic regression was used to construct a predictive model. Variables were removed if p>0.05.

Case descriptions

Case descriptions were derived from another part of this study, in which consultations with the SCEN physicians were registered and documented. A shorter version of the same questionnaire was completed by the physician and the consultant. The consultants supplied the report of the consultation that they wrote for the attending physician and for the review procedure, in which they describe the case in their own words, and explain why they think that the requirements of due care were or were not met. As examples of cases in which a patient who was not severely ill requested euthanasia, parts of the descriptions of two such patients have been translated.

RESULTS

According to the GPs, being tired of living was one of the important reasons for the request for EAS in 14% of patients suffering from cancer (282/2056), 30% of patients with another severe disease (81/271), and for 74% of patients who had no severe physical or psychiatric disease (45/61). If it was an important reason, it played a major role in the request for 23% of patients suffering from cancer (66/282), 42% of patients with another severe disease (34/81), and 87% of patients who had no severe physical or psychiatric disease (39/45) (Fig. 1).

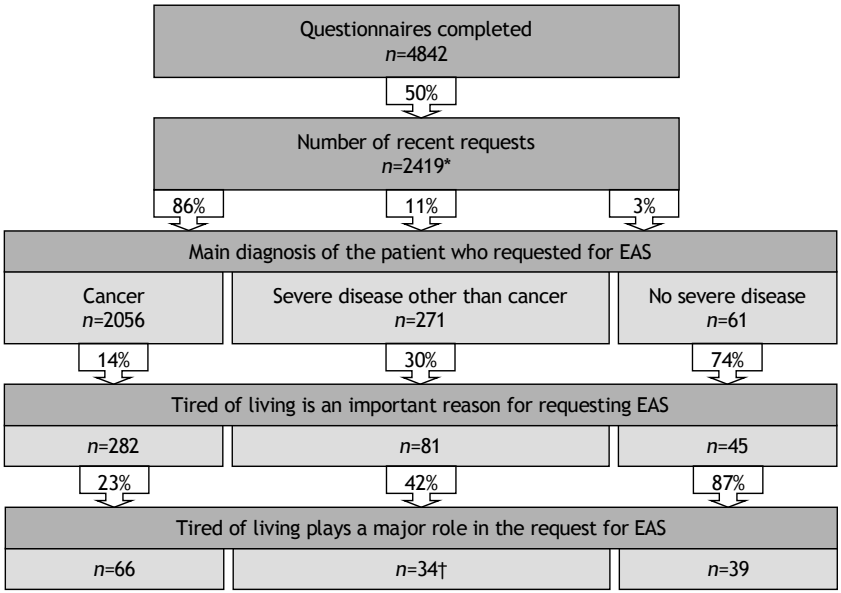

Fig. 1. Flow chart of the completed questionnaires

* In 31 cases we were unable to determine the presence or absence of severe disease.
† This group consists of patients with heart failure (5), COPD (5), MS/ALS (5), severe depression (3), CVA (2), arthritis or osteoporosis (2), kidney insufficiency (2), other diseases including combinations of above-mentioned diseases.

Characteristics and symptoms

Table 1 shows the characteristics and symptoms of patients who requested EAS, and for whom 'being tired of living' played a major role in the request. Of these 139 patients, 47% had cancer, 25% had another severe disease, and 28% had no severe disease. The majority of the patients were female (62%), and over 60 years of age (83%). In the absence of a severe disease, women formed an even larger majority of 90%. Patients who requested EAS in the absence of a disease were older than those who had a severe disease. The most frequently reported symptoms were feeling bad (80%), tiredness (72%) and inactivity (71%), independent of the absence or presence of a severe disease.

Table 1 Characteristics and symptoms of patients who requested EAS, and for whom being tired of living played a major role in the request

	Cancer *n*=66 *n*(%)	Severe disease other than cancer† *n*=34 *n*(%)	No severe disease *n*=39 *n*(%)	Total *n*=139 *n*(%)
Gender				
female	30(45)	21(62)	35(90)	86(62)
male	36(55)	13(38)	4(10)	53(38)
Age (years)*				
23–40	2(3)	1(3)	–	3(2)
41–60	13(20)	5(15)	1(3)	19(14)
61–80	39(59)	14(41)	12(32)	65(47)
81–100	12(18)	14(41)	24(65)	50(36)
Symptoms				
feeling bad	51(77)	32(94)	28(72)	111(80)
tired	51(77)	27(79)	22(56)	100(72)
not active	50(76)	26(76)	22(56)	98(71)
lack of appetite	44(67)	18(53)	13(33)	75(54)
depressed	18(27)	16(47)	17(44)	51(37)
pain	27(41)	10(29)	13(33)	50(36)
anxious	15(23)	11(32)	6(15)	32(23)
difficulty breathing	16(24)	12(35)	2(5)	30(22)
nauseous	22(33)	5(15)	1(3)	28(20)
coughing	12(18)	5(15)	2(5)	19(14)
vomiting	13(20)	1(3)	1(3)	15(11)
bedsores	3(5)	4(12)	4(10)	11(8)
no clear consciousness	4(6)	3(9)	1(3)	8(6)
confused	3(5)	–	1(3)	4(3)

*missing cases: 2

† this group consists of patients with heart failure (5), COPD (5), MS/ALS (5), severe depression (3), CVA (2), arthritis or osteoporosis (2), kidney insufficiency (2), other diseases including combinations of above-mentioned diseases (10).

Reasons

By definition, being tired of living was one of the reasons for all of the requests. In addition, feeling weak or tired, and deterioration or loss of dignity were the most frequently reported reasons for the request for EAS made by these patients (61% and 50%, respectively). For patients who had a severe disease other than cancer, disability and immobility were relatively important reasons. Reasons that were more often important for patients who suffered from cancer than for the other patients were: pointless suffering, not wanting to be a burden on their family anymore, pain, vomiting and fear of suffocating. Disability and immobility, and feeling depressed were more often reasons for the request for EAS from patients who suffered from a severe disease than for patients who did not. The physicians were asked whether these reasons given by their patients pertained to the current situation, the future situation, or both. In most cases the reasons pertained to the current situation (Table 2). Descriptions of two patients who requested EAS, but did not suffer from a severe disease are given in Boxes 1 and 2. Both requests were refused.

Table 2 Reasons for requests for EAS made by patients for whom being tired of living played a major role in the request

	Cancer *n*=66 *n*(%)	Severe disease other than cancer *n*=34 *n*(%)	No severe disease *n*=39 *n*(%)	Total *n*=139 *n*(%)
Reasons for request				
Tired of living	66(100)	34(100)	39(100)	139(100)
Weakness/tiredness	43(65)	20(59)	22(56)	85(61)
Deterioration/loss of dignity	43(65)	11(32)	16(41)	70(50)
Disability/immobility	33(50)	17(50)	11(29)	61(44)
Pointless suffering	40(61)	8(24)	7(18)	55(40)
Not wanting to be a burden on family anymore	35(53)	7(21)	10(26)	52(38)
Depressed	28(42)	11(32)	5(13)	44(32)
Pain	31(47)	4(12)	6(15)	41(29)
Vomiting	29(44)	2(6)	2(5)	33(24)
Fear of suffocating	27(41)	4(12)	2(5)	33(24)
Other	4(6)	–	3(8)	7(5)
Reasons pertained to				
current situation	34(52)	18(53)	24(62)	76(55)
future situation	7(11)	1(3)	3(8)	11(8)
both	25(38)	15(44)	12(31)	52(37)

Box 1 Part of a report of a consulting physician in an EAS procedure

A 91 year-old widow, lives independently in sheltered accommodation. She has no physical or psychiatric disease, but her hearing and visual abilities have deteriorated and she walks with difficulty. She often doesn't feel well, is tired most of the time and is not very active as a consequence. She seems to be alert and brisk, looks well-groomed, her speech is clear and coherent. There are definitely no indications of any mood disorder. She has requested euthanasia many times in recent years, because "she doesn't enjoy life anymore". This is mainly because of her loss of all meaningful contacts with relatives and fellow residents.

Box 2 Part of a report of a consulting physician in an EAS procedure

A 92 year-old woman has asked her physician to perform euthanasia many times in the past 10 years, but the physician never gave her a direct answer to this request. When asked why she has never insisted, she said that she was taught as a child not to complain about pain or other things, and that she has learned to make fun of situations in which one should really stick up for oneself.
She had surgery when she was 82 for a colon carcinoma. She was not expected to survive for more than 2 years after the surgery, and could accept that "I had reached the age to go", she said. Unexpectedly, there have been no signs of cancer since the surgery.
She has had pains in her abdomen ever since the surgery. She finds it difficult to keep her balance, and falls frequently, but has been miraculously free from fractures until two months ago, when she broke her left upper arm. Due to a serious macular degeneration she is unable to read, write or watch television. Her husband and stepdaughter are both dead, and she never had any children of her own, due to infertility problems. All the friends of her own age have died and she has become increasingly lonely. Several attempts have been made to alleviate her pain, but all the painkillers increase her dizziness. Every night she hopes that she will die in her sleep. She has considered and rejected suicide, because she is afraid her attempt will fail, and would only worsen her situation. She now hopes that her physician will seriously consider her request.

Decisions

Fig. 2 shows the physician's decision according to diagnosis. More than half of the requests made by patients suffering from a severe disease other than cancer, or patients who were not suffering from a severe disease, were refused (56% and 54%, respectively), but fewer requests from patients suffering from cancer were refused (14%). In all groups it seldom occurred that no decision was made or that the patient withdrew the request.
Table 3 shows whether the requirements of due care were met when the request was granted, refused, no decision was made or the patient withdrew the request. In 45% of all cases there were treatment alternatives, and in 9% these treatments were even possibly curative. The suffering was more often utterly hopeless (47%) than utterly unbearable (23%). The majority of these patients were considered to be competent (88%). When a request was granted there were more often no treatment alternatives, the request was more explicit, the suffering was more severe and the patient was always competent. For patients who withdrew their request there were often alternative treatment options (79%) that, when applied, alleviated the suffering or, when refused, made it possible for the physician to convince his or her patient that EAS was only possible if treatment was attempted, and thereby persuaded the patient to withdraw the request.

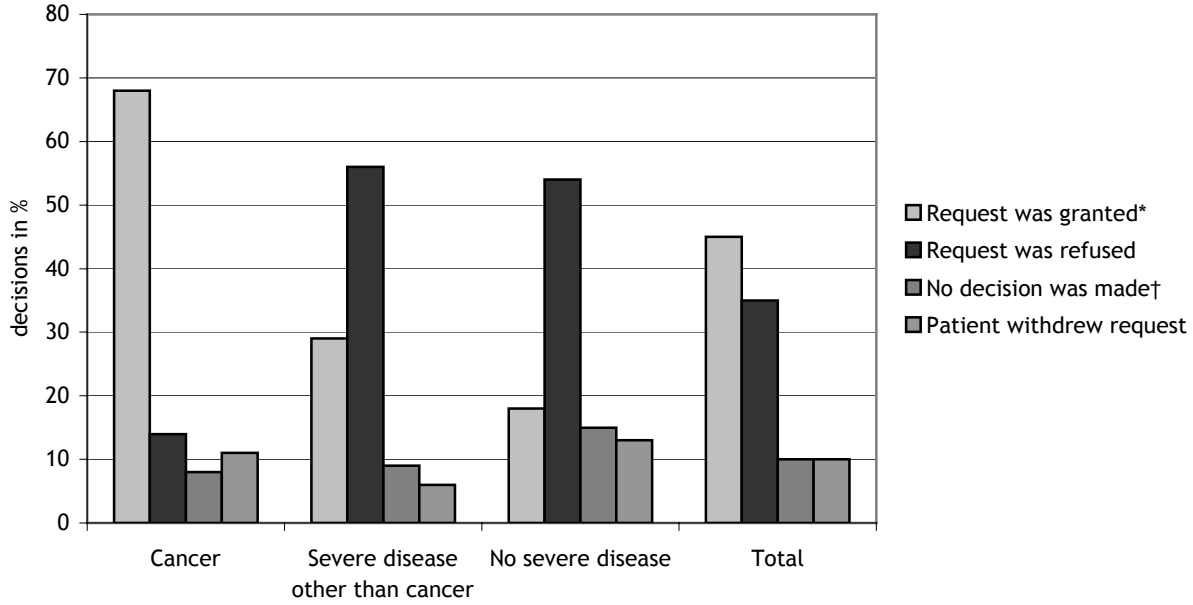

Fig. 2. Histogram of the physician's decision according to diagnosis in patients who requested EAS, and for whom being tired of living played a major role in the request

*The category 'request granted' consists of 45 cases of euthanasia, 11 cases of physician-assisted suicide and 6 cases in which the request was granted but the patient had died of natural causes before the actual performance.
†The category 'no decision was made' consists of 12 cases in which the patient had died before a decision was made, and 2 cases in which a definite decision had not been made yet at the time of the survey.

Table 3 Fulfillment of the requirements of due care at the time of completion of the decision-making process concerning patients in whose request for EAS being tired of living played a major role

	Request granted *n*=62 *n*(%)	Request refused *n*=49 *n*(%)	No decision *n*=14 *n*(%)	Patient withdrew request *n*=14 *n*(%)	Total *n*=139 *n*(%)
Treatment alternatives					
No	54(87)	13(27)	7(50)	3(21)	77(55)
Yes	8(13)	36(73)	7(50)	11(79)	62(45)
Curative treatment alternatives	—	10(20)	2(14)	1(7)	13(9)
Palliative treatment alternatives	8(13)	33(67)	6(43)	10(71)	57(41)
treatment applied, request withdrawn	—	7(14)	2(14)	6(43)	15(11)
treatment applied, request maintained	4(6)	17(35)	3(21)	1(7)	25(18)
patient refused treatment	4(6)	11(22)	2(14)	4(29)	21(15)
treatment not applied for another reason	—	1(2)	—	—	1(1)
Explicit request					
Utterly	52(84)	17(35)	5(36)	3(21)	77(55)
To a high degree	8(13)	26(53)	7(50)	8(57)	49(35)
To a lesser degree	2(3)	6(12)	2(14)	3(21)	13(9)
Average number of requests (min.—max.)*	7,9 (1—25)	5,2 (1—30)	3,1 (2—6)	6,2 (1—31)	6,4 (1—31)
The extent of unbearable suffering†					
Utterly	30(48)	—	—	1(8)	31(23)
To a high degree	26(42)	15(33)	6(46)	1(8)	48(36)
To a lesser degree	6(10)	30(67)	7(54)	11(85)	54(41)
The extent of hopeless suffering‡					
Utterly	49(80)	5(10)	8(57)	2(14)	64(47)
To a high degree	10(16)	11(23)	3(21)	7(50)	31(23)
To a lesser degree	2(3)	32(67)	3(21)	5(36)	42(31)
Patient competent‡					
Yes	61(100)	37(77)	13(93)	9(64)	120(88)
Not completely	—	9(19)	1(7)	4(29)	14(10)
Not at all	—	2(4)	—	1(7)	3(2)
Not (fully) competent because:					
Depression/ in mourning process/ psychiatric disorder	—	10(20)	1(7)	2(14)	13(9)
Other	—	1(2)	—	3(21)	4(3)
Consultation‡					
Yes	58(95)	34(69)	9(69)	7(50)	108(79)
No	3(5)	15(31)	4(31)	7(50)	29(21)

*missing cases: 10
†missing cases: 6
‡missing cases: 2

Table 4 Bivariate and multivariate analysis of the determinants of the probability of granting a request for EAS in which being tired of living played a major role (*n*=104, 7 missing cases)

4a bivariate

	Odds ratio	95% CI
hopeless suffering	59.0	12.8–273.0
absence of alternatives	18.7	7.0–49.7
unbearable suffering	18.7	6.6–53.1
explicit request	9.8	4.0–24.0
higher number of requests	6.4	2.7–15.2
severe disease	5.9	2.2–15.5
absence of depressive symptoms	5.8	2.4–14.1
pain	5.0	2.1–12.0
gender of the physician (male)	4.1	1.5–11.0
age of the patient (younger)	3.7	1.2–12.1
age of the physician (older)	2.5	1.1–6.0
gender of the patient (male)	2.5	1.1–5.8

4b multivariate*

	p	Odds ratio	95% CI
hopeless suffering	0.001	21.3	3.5–129.4
absence of alternatives	0.010	5.9	1.5–22.3
unbearable suffering	0.016	6.1	1.4–26.9
absence of depressive symptoms	0.046	4.5	1.0–19.6

*This model was based on 62 granted requests and 49 refused requests, one or more variables were missing for 7 of these cases.

Table 4a shows several factors that in a bivariate analysis were found to be associated with a request being granted or refused. All explored variables were significant. The strongest associations with granting a request were found for a higher degree of hopeless suffering, the absence of alternatives, a higher degree of unbearable suffering and a more explicit request.

Table 4b shows a predictive model computed with a multivariate backward analysis, using the variables in 4a. Variables were left out in the following sequence: severe disease, age of the patient, age of the physician, number of requests, pain, and gender of the patient. Subsequently, gender of the physician and explicitness of the request were left out, but both these variables had a $p<0.1$. Apparently, male physicians were more likely to grant requests than female physicians. Also, the explicitness of the request was more important than the number of requests, and was apparently not solely defined by the number of requests. In the final predictive model, a higher degree of hopeless and unbearable suffering, the absence of treatment alternatives and the absence of depressive symptoms proved to be determinants of the physician's decision to grant a request.

DISCUSSION

One limitation of this study was that only physicians, and even more so, that only GPs were interviewed. Physicians might tend to emphasize the medical aspects of the suffering, whereas the patients themselves would sooner mention being tired of living as an issue in their situation. This would lead to an under-estimation of the occurrence of being tired of living as an important reason for patients suffering from a severe disease to request EAS. Another limitation in using this study to investigate the aspect of 'being tired of living', was that the study was not designed to do so, and therefore not all the relevant variables were

measured. However, one advantage of this approach was that any form of subject-related bias was avoided, as a result of which we think that we are able to present a representative overview of recent cases, although we cannot rule out the possibility that some physicians might have described 'memorable cases', instead of their most recent case. Furthermore, the magnitude of the study made it possible to identify a considerable number of cases involving a relatively rare phenomenon, enabling analysis of the factors that influenced the decision-making.

Main findings

In more than one in seven requests for EAS made by patients suffering from a severe disease, being tired of living was an important reason for the request, according to the GP. For patients who did not suffer from any physical or psychiatric disease, being tired of living was an important reason in almost three out of four requests for EAS. However, in absolute numbers, even if being tired of living was not only one of the reasons for the request but, in fact, played a major role in the request, the patients were still most likely to suffer from the advanced stages of cancer or some other severe disease.

In patients who were over 40 years of age, being tired of living played a major role in requests for EAS in all age-categories; compared with all cases of EAS, these patients were older, but when compared with all deaths in 2001, they were distributed equally over the age-categories (van der Wal *et al.* 2003). Women were over-represented in these requests (62%), especially in the absence of a severe diseases (90%).

Patients with cancer or some other severe disease have a higher symptom burden than patients who do not have a severe disease. This is according to expectations, especially since the scale used to measure the symptoms was an adaptation of a scale developed for use on a palliative care unit (Bruera *et al.* 1991). However, these symptoms occurred more frequently than might have been expected in patients who did not suffer from a severe disease. Each of the three symptoms that occur most frequently in patients with cancer or some other severe disease —feeling bad, tired and inactive— occurred in more than half of the patients who did not suffer from a severe disease. This implies that non-severe diseases and old age can cause symptoms that are similar to those caused by severe diseases. The case presented in the second box may make this more understandable.

In a bivariate analysis of the determinants of granting or refusing a request for EAS, requests made by younger patients and male patients were significantly more likely to be granted. This can be explained by an association with cancer. Requests from patients with a severe disease were also significantly more often granted than requests from patients who did not have a severe disease. However, when constructing a predictive model, other factors prove to be more important: unbearable and hopeless suffering, the absence of alternatives treatments and the absence of depressive symptoms. The absence of depressive symptoms was also found to be an important factor in granting a request for EAS in a general patient population (Meier *et al.* 2003). This seems to be self-evident, since depressive symptoms could indicate a depression that may be treatable. Indeed, research has shown that patients with depressive symptoms are more likely to change their minds about wanting EAS (Emanuel *et al.* 2000).

Whether or not the requirements of due care are met is more important in the assessment than the presence or absence of a severe disease. In the requests that were granted, the requirements of due care were not always met, but similar due care was provided as in all cases of EAS (Haverkate *et al.* 2000).

Medical domain

It seems illogical to consider a request for EAS in which being tired of living plays a major role as something that falls within the expertise of a physician when a patient *does* suffer from a severe disease, and as outside the expertise of the physician when a patient *does not* suffer from a severe disease, since this borderline implies that the problems associated with old age do not fall within the medical domain. However, this may not be a logical assumption, because an increasing number of medical problems associated with old age can be alleviated or cured by a physician. Effective treatment is available for cataract,

hearing impairments, angina, osteoarthritis, impotence, depression, and other common conditions in the elderly (Ebrahim, 2002; Rothschild *et al.* 2000). The description of normal ageing, i.e. a series of cumulative, universal, intrinsic and deleterious changes, also applies to many chronic diseases (Izaks and Westendorp, 2003). Depending on our understanding of —and ability to cure— the various consequences of old age, we define some as diseases and others as the consequences of a normal ageing process (Izaks and Westendorp, 2003; Leibovici and Lievre, 2002; Smith, 2002; Wessely, 2002). This is a matter of definition, making the distinction between normal ageing and disease in older people arbitrary (Izaks and Westendorp, 2003). As described in the Introduction, people with severe diseases do not usually request EAS exclusively for medical reasons, but also because of the complex psychological effects of their medical condition and its consequences. A committee installed by the Royal Dutch Medical Association (RDMA) concluded in December 2004 that a medical cause should not be a requirement for EAS (Dijkhuis and Committee Members, 2004). One argument, according to this committee, was that the legal demarcation of a medical cause does not reflect the complexity of medical practice. Our study supports this argument by showing that the burden of symptoms is high in patients who request EAS in the absence of a severe disease. Since requests for EAS in which being tired of living plays an important role are assessed according to the requirements of due care, it seems that excluding patients who suffer 'only from old age' from EAS legislation is not necessarily justified. In response to the report issued by their committee, the RDMA acknowledged the complexity of medical practice in cases where people 'suffer from life', but added that more clarification is necessary to decide whether or not this falls within the medical domain and, thus, whether physicians can or can not consider granting requests for EAS in such cases. It is not possible to predict whether or not EAS in the absence of a severe disease will be allowed in the Netherlands in the future, because both the medical authorities and the legal authorities have left room for a shift in either direction.

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Chapter 4

A 'suicide pill' for older people: attitudes of physicians, the general population and relatives of patients who died after euthanasia or physician-assisted suicide in the Netherlands

"Mijn ideaal is dat oude mensen die op zichzelf zijn aangewezen, naar een arts kunnen lopen —hetzij hun huisarts, hetzij een daartoe aangewezen arts— om de middelen te verkrijgen waarmee zij op het moment dat hun dat zelf aangewezen voorkomt, een eind aan hun leven kunnen maken op een manier die voor henzelf en voor hun omgeving aanvaardbaar is."

Huib Drion

ABSTRACT

Objective : To investigate, in the Netherlands, the attitudes of physicians, the general public and relatives of patients who died of euthanasia or physician-assisted suicide (EAS) with regard to EAS in the absence of a severe disease and the availability of a 'suicide pill'.

Methods : In the Netherlands, 410 physicians (208 clinical specialists, 125 general practitioners and 77 nursing home physicians) and 87 relatives of patients who died of EAS were interviewed, and 1379 members of the general public completed a questionnaire.

Results : Most of the physicians, general public and relatives thought that everybody has the right to decide about their own life and death. The general public and the relatives were more in favor of enabling older people to obtain medication to end their life if they so wish than the physicians were. 15% of the general public and 36% of the relatives thought that a 'suicide pill' should be made available. The reason why the relatives wanted a 'suicide pill' to be made available was the right to decide about one's own life and death. Main reasons for being against were "fear of using such a pill in a depressed period or on impulse" (42%), and "a preference for the involvement of a physician" (30%). In all groups, religious beliefs were associated with a less supportive attitude towards self-determination at the end of life. 74% of the physicians considered it inconceivable that they would ever grant a request for EAS in the absence of a severe disease.

Conclusions : The availability of a 'suicide pill' would give some people the self-determination they want, but the absence of safeguards makes it a bridge too far for the majority.

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In the Netherlands the performance of euthanasia has become widely accepted over the past few decades: the number of proponents has increased from 50% to almost 90%, and the number of opponents has decreased from almost 50% to 10% (Social and Cultural Planning Office, 1966—1998). In the opinion polls, euthanasia was defined as the administration of lethal drugs by a physician to a suffering patient at the request of the patient. Although the cause of suffering was not always clearly defined in public debates about euthanasia, it was usually assumed the patient was severely, and often terminally ill.

In recent years a debate has evolved in the Netherlands about euthanasia and physician-assisted suicide (EAS)[a] for patients who suffer from the consequences of old age, but who do not suffer from a severe disease. A general practitioner who had granted such a request from one of his patients in 1998, was prosecuted for several years. In 2002, he was convicted for assisted suicide by the Dutch Supreme Court. This case made clear that EAS in the absence of a severe disease was illegal in the Netherlands. The prosecution of this general practitioner gave new impulse to the debate about the so-called 'Drion Pill'. A Drion Pill does not in fact exist, but is a hypothetical 'suicide pill' that would enable older people to end their life if they wished to do so, possibly without interference of a physician. It is named after Mr. Drion, an emeritus professor of civil law and former vice-president of the Supreme Court, who first made a plea for such a pill in 1991 (October 19). In 2001, Mrs. Borst-Eilers, who was then Minister of Public Health, stated that she would "not be against" the availability of a 'suicide pill' for very old people who are through with life. Furthermore, she said that she did not think that being tired of living was a matter that could be judged by physicians or regulated in EAS legislation (Oostveen, 2001). This led to turmoil in the Dutch parliament, especially since she made these statements shortly after the new EAS legislation had come into effect, legalising cases of EAS that fulfilled a number of strict requirements for prudent practice. This was only approved after an extensive debate in parliament, in which an understanding was reached that the new legislation would only apply to patients who suffered from a severe disease.

In view of this ongoing debate, it would be important to have insight into the attitudes and opinions of the general population and physicians with regard to these issues. However, almost no data are available (Holsteyn and van Trappenburg, 1998; van Trappenburg and Holsteyn, 2001). This study therefore aims to obtain insight in the attitudes and opinions of the general population and physicians with regard to EAS in the absence of a severe disease, and the availability of a 'suicide pill' for older people. The attitudes of relatives of patients who died after EAS were also studied, since it was expected that they would have given more thought to these matters. Another aim was to analyse the determinants of the attitudes in these three groups of people.

METHODS

Euthanasia is defined as the administration of drugs by a physician with the explicit intention of ending a patient's life at his/her explicit request, and physician-assisted suicide is defined as the prescription or supply of drugs with the explicit intention to enable a patient to end his/her own life at his/her explicit request.

[a] Euthanasia and PAS (physician-assisted suicide) come under the same law in the Netherlands, and the same requirements apply. Even though the RDMA (Royal Dutch Medical Association) has advised to choose PAS instead of euthanasia when possible, the rate of PAS remains remarkably low (Onwuteaka-Philipsen *et al*. 2003). In the context of patients who do not have a severe disease, it might be more logical to talk about PAS, but since PAS is not a commonly known term in the Netherlands, we used EAS consistently in our study and in this report.

This article describes three studies that were all performed as part of a large-scale study of medical decision-making at the end of life, commissioned by the Minister of Public Health and the Minister of Justice (Onwuteaka-Philipsen *et al*. 2003).

Physician interview study

In 2002, 208 clinical specialists (cardiologists, surgeons and specialists in internal medicine, pulmonology and neurology), 125 general practitioners (GPs) and 77 nursing home physicians (NHPs) were interviewed. The interviewers were physicians who had received specific training for this purpose. The GPs and NHPs were asked in a face-to-face interview about the conceivability of granting a request for EAS in the absence of a severe disease. Only GPs and NHPs were asked, because it was assumed that the patients of clinical specialists would often not meet the requirement: i.e. the absence of a severe disease. All the physicians (including the clinical specialists) were asked to give their opinions on several statements in a written questionnaire received from the interviewer. A written questionnaire was chosen because it would make it easier for the respondent to understand complicated statements. The response was 87%. Possible determinants of attitudes that were measured were age, gender, religious beliefs, experience with (requests for) EAS, and location of work in the Netherlands.
To reflect the attitudes of all physicians in the Netherlands, the percentages are weighted for the specialty of the physician.

General population survey

1379 members of the general population completed a questionnaire in September 2002. These people were participants in an existing consumer panel selected by the NIVEL (Netherlands Institute for Health Services Research), selected to be representative of the population of the Netherlands above the age of 18 years. The only divergence was that women were over-represented in the panel (60%), and this percentage was also found among the respondents. The written questionnaires were designed to be similar to those used for the physicians, but after a pilot, all medical terms were replaced by 'ordinary' language, to make the questionnaires more comprehensible for the general population. The response was 78%. Possible determinants of attitude that were measured were age, gender, religious beliefs, level of education, type of insurance, experience with requests for EAS in their surroundings, self-reported health status (5-point scale) and type of household.

Surviving relatives interview study

87 relatives of patients who had died after EAS were interviewed. The relatives were selected through a sample of 167 physicians who had reported EAS to a regional review committee in 2001 or 2002. The sample of physicians was stratified according to specialty, and consisted of clinical specialists (34%), GPs (49%) and NHPs (16%). These physicians were asked to contact the relative who had been most involved in caring for the patient, and ask them whether they would be willing to be interviewed about their experiences and attitudes. Of these 167 physicians, 8 were unwilling to contact the relative because they did not want to burden him/her, 16 were unable to contact the relative, and 46 did not contact the relative but gave no explicit reason. Of the 97 relatives (58%) who were contacted, 3 were unwilling to be interviewed because of lack of time, and 7 said that it was too difficult for them to talk about the deceased. A total of 87 (90%) relatives agreed to be interviewed. Possible determinants of attitude that were measured were age, gender, religious beliefs, level of education and type of insurance.

Analysis

In the analysis of the determinants of attitudes, people who were 'neutral', 'didn't know' or answered 'maybe', were not included. All the determinants that were mentioned above were tested for association with four statements (Tables 1 and 2). The specialty of the physician was also tested. We used a Chi-square test to determine whether

relationships between background characteristics and agreement with statements were significant. Self-reported health status, measured on a 5-point scale, was dichotomized by combining the first two categories (very good and good) and the last three categories (moderate to bad). The type of household was dichotomized by the presence or absence of children, location of work was sub-divided into 4 groups: north, south, east and west. Age and level of education were analysed as an ordinal scale, and examined for their relationship with attitude by means of a linear Chi-square. Only the relationship of the following determinants is shown in the Tables: age, gender, experience, level of education and religious beliefs. The other determinants are only mentioned in the text if they were related to attitude.

RESULTS

Self-determination at the end of life

Table 1 shows that the majority of the physicians (56%), the general population (68%) and the relatives (74%) agreed with the first statement: *"Everybody has the right to decide about their own life and death"*. The general population more often agreed (45%) than disagreed (35%) with the second statement: *"Very old people should be able to obtain medication with which they can end their life if they so wish"*, while the physicians predominantly disagreed (56%) with this statement.

The first statement (*"Everybody has the right to decide about their own life and death"*) was agreed with more often by people who did not have religious beliefs. This applied to the physicians (70% vs. 59%), the general population (90% vs. 72%) and the relatives (94% vs. 79%, not significant). Those in the general population with previous experience of (requests for) EAS in their surroundings agreed more often (87% vs. 77%). Previous experience of performing EAS had no association with the opinions of the physicians with regard to this statement. Similar determinants were found for the second statement (*"Very old people should be able to obtain medication with which they can end their life if they so wish"*). People who did not have religious beliefs and people who had previous experience of (requests for) EAS in their surroundings agreed more often. There was also a linear trend, with older physicians agreeing more often with this statement (from 16% to 37%).

Table 1 Frequencies with 95% Confidence Intervals (CI) and determinants (agreement vs. disagreement, Chi-square probability <.05 in bold) of attitudes of physicians, the general population and relatives of patients who died after euthanasia or physician-assisted suicide

	Statement 1: Everybody has the right to decide about their own life and death			**Statement 2:** Very old people should be able to obtain medications with which they can end their life if they so wish	
	Physicians*	**General Population**	**Relatives**	**Physicians***	**General Population**
Frequencies	*n*=410 % (95% CI)	*n*=1379 % (95% CI)	*n*=87 % (95% CI)	*n*=410 % (95% CI)	*n*=1379 % (95% CI)
Completely agree	34 (29–39)	42 (39–45)	Not an option	5 (3–7)	22 (20–24)
Agree	22 (18–26)	26 (24–29)	74 (64–83)	20 (16–23)	23 (21–26)
Neutral	13 (10–16)	15 (13–17)	14 (7–23)	19 (15–23)	20 (18–22)
Disagree	15 (12–19)	8 (6–9)	12 (6–20)	25 (20–29)	17 (15–19)
Completely disagree	15 (12–19)	10 (8–11)	Not an option	32 (27–36)	18 (16–20)

Table 1 continued

	Statement 1: Everybody has the right to decide about their own life and death			**Statement 2:** Very old people should be able to obtain medications with which they can end their life if they so wish	
	Physicians*	**General Population**	**Relatives**	**Physicians***	**General Population**
Determinants†	*n*=355 % (complete) agreement	*n*=1175 % (complete) agreement	*n*=74 % (complete) agreement	*n*=333 % (complete) agreement	*n*=1099 % (complete) agreement
Age	*p*=.78	*p*=.07	*p*=.56	***p*=.01**	*p*=.17
<30 years	—	81	‡	—	53
30—39 years	60	80	‡	**16**	49
40—49 years	67	87	84	**28**	70
50—65 years	65	78	94	**37**	61
>65 years	—	74	79	—	53
Gender	*p*=.67	*p*=.36	***p*=.04**	*p*=.77	*p*=.25
Male	67	78	**77**	30	55
Female	64	81	**93**	28	58
Experience††	*p*=.98	***p*=.00**		*p*=.51	***p*=.00**
Yes	66	**87**	—	31	**67**
No	66	**77**	—	28	**53**
Level of education‡‡		*p*=.74	*p*=.36		*p*=.17
Low	—	79	83	—	59
Intermediate	—	80	85	—	53
High	—	81	92	—	59
Religious beliefs	***p*=.03**	***p*=.00**	*p*=.05	***p*=.00**	***p*=.00**
No	**70**	**90**	94	**38**	**67**
Yes	**59**	**72**	79	**19**	**49**

* Weighted percentages.
† (Completely) agree versus (completely) disagree, respondents who are neutral are not included.
‡ Relatives in these age-groups were added to the 40—49 age-group.
†† For physicians: experience with granting a request for euthanasia or physician-assisted suicide, for the general population: experience of requests for euthanasia or physician-assisted suicide in their surroundings.
‡‡ Low: no education/primary school/lower vocational/lower secondary;
Intermediate: intermediate or higher secondary/intermediate vocational;
High: higher vocational/university.

A 'suicide pill'

When specifically asked about a 'suicide pill', 15% of the general population thought that it should be made available, and 32% answered 'maybe' (Table 2, question 1). When asked whether they could imagine ever wanting to have such a pill at their own disposal, 24% of the general population said that they could (question 2). The relatives of patients who had died after EAS were more in favor of the availability of a 'suicide pill' (36% yes and 11% maybe). They could also more often imagine wanting such a pill for themselves, when compared with the general population (38% vs. 24%). The relatives of patients who had died after EAS were more in favor of the availability of a 'suicide pill' (36% yes and 11% maybe). They could also more often imagine wanting such a pill for themselves, when compared with the general population (38% vs. 24%). The relatives were asked what they took into consideration if they were in favor or against a 'suicide pill' (Table 3). The relatives who were in favor of a 'suicide pill' always mentioned the right to decide about one's own life. They also often mentioned a specific situation in which they would want to take such a pill. The considerations that were most frequently mentioned by those who were against a 'suicide pill' were: fear of taking such a pill when depressed or on impulse, preference for EAS (with the involvement of a physician), and fear of misuse for murder. The questions about a 'suicide pill' were most often answered positively by people with no religious beliefs (Table 2). In the general population, people with previous experience of (requests for) EAS in their surroundings were more often in favor. There was also a linear trend, with older people more often in favor of a 'suicide pill'. Furthermore, people with a lower level of self-reported health status more often thought that a 'suicide pill' should be made available (32% vs. 23%, p=.01) and could more often imagine wanting such a pill for themselves (44% vs. 33%, p=.00). The same applied to people who had no children: they more often thought that a 'suicide pill' should be made available (30% vs. 19%, p=.00), and they could more often imagine wanting such a pill for themselves (43% vs. 29%, p=.00) (data not shown in Table).

Table 2 Frequencies with 95% Confidence Intervals (CI) and determinants ('yes' versus 'no', Chi-square probability <.05 in bold) of attitudes of the general population and relatives of patients who died after euthanasia or physician-assisted suicide

	Question 1: Do you think a pill to commit suicide should be made available for elderly people who do not want to live any longer (even if they do not suffer from a severe disease)?		**Question 2:** Can you imagine ever wanting to have such a pill at your own disposal?	
	General Population	**Relatives**	**General Population**	**Relatives**
Frequencies	*n*=1379 % (95% CI)	*n*=87 % (95% CI)	*n*=1379 % (95% CI)	*n*=87 % (95% CI)
Yes	15 (14—17)	36 (26—47)	24 (22—26)	38 (28—49)
Maybe	32 (30—34)	11 (6—20)	25 (23—28)	7 (3—14)
No	46 (43—49)	46 (35—57)	42 (39—44)	52 (41—62)
Don't know	7 (5—8)	7 (3—14)	9 (7—10)	3 (1—10)
Determinants*	*n*=846 % Yes	*n*=71 % Yes	*n*=905 % Yes	*n*=78 % Yes
Age	***p*=.00**	*p*=.28	***p*=.03**	*p*=.20
<30 years	**17**	†	**35**	†
30—39 years	**16**	†	**25**	†
40—49 years	**35**	55	**48**	48
50—65 years	**31**	40	**42**	48
>65 years	**28**	38	**37**	29
Gender	*p*=.72	*p*=.22	*p*=.70	*p*=.27
Male	25	35	36	35
Female	26	50	37	48
Experience	***p*=.00**		***p*=.00**	
Yes	**38**	—	**54**	—
No	**21**	—	**30**	—
Level of education‡	***p*=.01**	*p*=.77	*p*=.06	*p*=.54
Low	**24**	41	36	41
Intermediate	**20**	45	32	36
High	**36**	46	45	50
Religious beliefs	***p*=.00**	***p*=.02**	***p*=.00**	***p*=.00**
No	**36**	**59**	**49**	**59**
Yes	**18**	**31**	**27**	**27**

* 'Yes' versus 'no', respondents who said 'maybe' or 'don't know' are not included

† Relatives in these age-groups were added to the 40—49 age-group

‡ Low: no education/primary school/lower vocational/lower secondary
Intermediate: intermediate or higher secondary/intermediate vocational
High: higher vocational/university

Table 3 Considerations of relatives of patients who died after EAS (euthanasia or physician-assisted suicide) in favor or against a 'suicide pill' (*n*=71*)

In favor (*n*=31)	n	Against (*n*=43)	n
Right to decide about one's own life	31	Fear of taking such a pill when depressed or on impulse	18
I would want to use such a pill if I…	18	Prefer EAS (with the involvement of a physician)	13
… would be terminally ill	7	I'm afraid such a pill would be misused for murder	5
… am old and tired of living	5	There should be some form of control on EAS, this becomes impossible with a suicide pill	4
… would be dependent/cannot do anything anymore	4	I cannot imagine a situation in which one would want to use such a pill	4
… would not be able to get EAS	2	There is no need for such a pill	2
… cannot have interaction of value with other people anymore	1	It is against my religious beliefs	1
… if there would be war and I would not have control over my life	1	I think it's a scary idea	1
There should be a pill, but there should also be conditions for availability	5	You cannot just step out when life still has something to offer	1

*Three relatives who were in favor also mentioned considerations against a 'suicide pill'.

Conceivability of granting a request

Of the GPs and NHPs, 26% considered it conceivable that they would ever grant a request for EAS from a patient who did not have a severe physical or psychiatric disease. They considered it conceivable in situations in which "someone is dependent and has physical problems" (29%), "someone is very old" (28%), "someone has become isolated, for instance due to the death of others of the same generation" (22%), and when "there is no chance of improvement in the situation" (19%). The main reasons given by the 74% of physicians who considered it inconceivable to grant such a request were: "it is not my task as a physician to grant such requests" (50%), "there is no justification for EAS in the absence of a severe disease" (21%), "it is too much of a burden emotionally" (19%), "it is against my religious beliefs or philosophy of life" (18%), and "because of possible prosecution" (13%).

DISCUSSION

In the Netherlands, most physicians, members of the general population and relatives of a patient who died after EAS agree with the statement *"everybody has the right to decide about their own life and death"*, but physicians disagree more often than the general population and the relatives. Of course, this statement can be interpreted as meaning a range of different things, from a very restricted interpretation 'everybody has the right to refuse treatment' to a very liberal interpretation 'everybody has the right to commit suicide'. When confronted with the practical consequences of the more liberal interpretation in the form of the statement *"very old people should be able to obtain medication with which they can end their life if they so wish"*, fewer physicians and fewer members of the general population agree. However, still more of the general population agree than disagree, while most physicians disagree. Apparently, physicians are less in favor of self-determination at the end of life than the general population and the relatives.

A small minority (15%) of the general population thinks that a 'suicide pill' should become available, but many (39%) are not sure or do not know. The relatives more often think that a 'suicide pill' should become available, and they also more often have an opinion about the matter. This is consistent with the finding that the general population with previous experience of requests for EAS in their surroundings are more often in favor of a 'suicide pill'. It is

not clear whether previous experience of EAS in the surroundings determines attitude towards EAS, or attitude determines experience.

It is notable that more of the general population can imagine wanting to have a 'suicide pill' at their own disposal, and less think that a 'suicide pill' should be made available for everyone. The reasons given by the relatives for wanting a 'suicide pill' to be made available concerned deciding about one's own life. Most of the reasons for not wanting such a pill to be made available concerned fear of misuse and lack of control.

It can be said, in general, that people with religious beliefs are more likely to be less in favor of self-determination at the end of life. This is consistent with the results of other studies (Brett and Jersild, 2003; Kelly *et al*. 2002; Bachman *et al.* 1996; Caddell and Newton, 1995). However, a novel result is that members of the general population with previous experience of requests for EAS in their surroundings are more often in favor of self-determination at the end of life. Members of the general population with a higher level of education are more often in favor of the availability of a 'suicide pill'. Literature on the effect of the level of education on attitude towards EAS is contradictory (Caddell and Newton, 1995; Suarez-Almazor, Belzile *et al.* 1997). Other novel determinants are a lower level of self-reported health status and the absence of children, but these only determined attitude about a 'suicide pill'.

As discussed in the introduction, the debate about a 'suicide pill' has been ongoing in the Netherlands for the past ten years. Since it originated from the EAS debate, an important issue is: why are physicians, and physicians only, entitled to judge the validity of requests for EAS and to dispense lethal drugs? And who would be a competent distributor of a 'suicide pill'? In our view, these questions are only relevant if it can be demonstrated that many people are in favor of a 'suicide pill' or EAS in the absence of a severe disease. Therefore, the question of distribution has been avoided in the present study, and the research questions focus only on the acceptability of a 'suicide pill' and EAS in the absence of a severe disease, irrespective of who should and could be a provider of lethal drugs.

We can structure and analyse arguments about a 'suicide pill' from proponents and opponents through the so-called 'four-principles' approach to biomedical ethics, comprehending the principles of beneficence, justice, autonomy and non-maleficence (Beauchamp and Childress, 1994).

The debate started with Drion's argument of, which could be said to be mainly based on 'beneficence'. He argued that very old people would be able to be more at peace if they had medication at hand to end their life in a dignified way if the time had come in their opinion. He thought that it would mainly be a reassurance that in most cases would never be used. He also mentioned that in society there are already many available means to end one's life, such as trains and high buildings, but only a few members of society, e.g. physicians and pharmacists, have access to more dignified means. This argument is, in fact, based on 'justice'. He finally stated that there seems to be no argument against providing at least some old people with such medication; if they wanted such medication, and if they were very old and had no relatives who could be hurt by their suicide, they would thereby have a right to 'autonomy'.

Especially this last argument in favor of autonomy seems to appeal to those participants in our study who thought that a 'suicide pill' should be made available. However, respondents who were against a 'suicide pill' mentioned arguments that could be classified under the fourth principle, the principle of 'non-maleficence'.

Providing someone with the means to commit suicide would be wrong, in the same way as killing or taking life is wrong. On the other hand, the reason why killing or taking a life is wrong is because it is against the interests of the victim, who loses the future he would have had if the killing had not taken place. However, in the case of suicide, the decision to abandon such a future is made by the 'victim', making suicide a 'victimless crime', provided the person who commits suicide is capable of making well-considered decisions. However, many participants in this study questioned whether a decision to commit suicide is always well-considered. Not only were they concerned about the harm to the person who attempts suicide, but also about the harm to other people in society. The right to respect for autonomy can be overridden if the provision of 'suicide pills' endangers public health or can potentially

harm innocent people. Many possible types of harm can be imagined, such as bereavement of the relatives of the person who commits suicide, intentional misuse of the 'suicide pill' for murder, and accidents with lethal medication. It could even be said that making a 'suicide pill' available could threaten social stability, if this should lead to suicide becoming an accepted, common practice.

However, these harmful situations are speculations, some of which are unlikely to become reality. Respecting a person's autonomy requires more than obligations of non-intervention in personal affairs; it also includes obligations to maintain capacities for autonomous choice in others, while allaying fears and other conditions that destroy or disrupt their autonomous actions (Beauchamp and Childress, 1994).

It would seem that at least some arguments against the availability of a 'suicide pill' are based on practical problems, which could be surmounted with a stringent system of requirements, as in the case of EAS. However, some normative arguments against a 'suicide pill', such as the impropriety of the value judgement about the life of older people implied by a 'suicide pill' for older people, cannot be countered by any practical system. It would be beneficial for the clarity of the debate if practical and normative arguments would be separated, because practical problems only become relevant if a 'suicide pill' would be considered ethical.

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Part 3
Advance directives

Chapter 5

Frequency and determinants of advance directives concerning end-of-life care

"Death is the wish of some, the relief of many, and the end of all."

Seneca

ABSTRACT

Background : In the USA, the use of advance directives (ADs) has been studied extensively, in order to find opportunities to increase their use. Almost no data are available on the prevalence of advance directives in Europe.

Objectives : The aim of this study is to investigate the prevalence of advance directives in the Netherlands and to determine which factors are associated with the formulation of advance directives.

Methods : We investigated the prevalence of ADs and which factors were associated with formulation of an AD in the Netherlands, using samples of three groups: the general population up to 60 years of age, the general population over 60 years of age, and the relatives of patients who died after euthanasia or assisted suicide. We arranged the associated factors according to the three following components: predisposing factors (e.g. age, gender), enabling factors (e.g. education) and need factors (health-related factors).

Results : We found that living wills had been formulated by 3% of younger people, 10% of older people, and 23% of the relatives of a person who died after euthanasia or assisted suicide. Most living wills concerned a request for euthanasia. In all groups, 26—29% had authorized someone to make decisions if they were no longer able to do so themselves. Talking to a physician about medical end-of-life treatment occurred less frequently, only 2% of the younger people and 7% of the older people had done so. Most people were quite confident that the physician would respect their end-of-life wishes, but older people more so than younger people. In a multivariate analysis, many predisposing factors were associated with the formulation of an AD: women, older people, non-religious people —especially those who lived in an urbanized area— and people with less confidence that the physician would respect their end-of-life wishes were more likely to have formulated an AD. Furthermore, the enabling factor of a higher level of education, the need factor of contact with a medical specialist in the past 6 months, and the death of a marital partner were associated with the formulation of an AD.

Conclusions : Few people in the Netherlands have recorded their end-of-life wishes. If they had, they most often had advance directives concerning euthanasia, which are unlikely to be adhered to. The use of ADs should be further stimulated, provided adequate information about their legal value is given and more research into the barriers of following ADs in practice is done.

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When a patient becomes incompetent it may be difficult for relatives and physicians to make end-of-life decisions when they are not sure what the patient would have wanted. However, if the patient has an advance directive, or has talked about end-of-life preferences, this may make the decision-making easier and more in accordance with the patient's wishes.

Much attention has been paid to advance directives in the USA, and research concerning advance directives and how to stimulate patients to formulate them originates almost exclusively from the USA. We will first discuss the research on advance directives that has been carried out in the USA, and then move on to describe the situation in the Netherlands and the aims of this study.

Types and prevalence of advance directives in the USA

In the USA, the federal 'Patient Self-Determination Act' (PSDA) was implemented in 1991 to stimulate patients to express their wishes with regard to treatment at the end of their life. An important requirement of the PSDA was that health care organizations had to inform patients about their right to formulate advance directives concerning health care. Two types of advance directives in the USA are 'living wills' and 'durable power of attorney for health care'. In a living will the patients themselves specify which treatments they wish to receive and which treatments they would want to be foregone, and under which circumstances. In a durable power of attorney, the patients authorize another person to speak or decide on their behalf (Miles *et al.* 1996).

After the enactment of the PSDA the formulation of advance directives increased considerably in some populations, and the PSDA led to better documentation of advance directives in medical records. Two years before the enactment of the PSDA, 5% of nursing home residents had an advance directive, but two years after the enactment this had increased to 35% (Bradley *et al.* 1998). In a cohort of seriously ill hospitalized patients, 21% had an advance directive. This rate was similar before and after the PSDA, and even after an additional intervention. The documentation of advance directives , however, did improve, only 6% of which were mentioned in the medical records before the PSDA, 35% were documented after the PSDA, and 78% after the PSDA with an additional intervention (Teno *et al.* 1997). It was considered somewhat disappointing in the USA that studies concerning advance directives after the enactment of the PSDA showed only a limited increase in the prevalence of advance directives in the overall population.

Existing evidence suggests that people are unable or unwilling to formulate advance directives until they grow older or become ill. This observation is supported by several prevalence studies. The prevalence of advance directives in adults was found to be 18% (De Luca Havens, 2000), and approximately one third of older adults, seniors in health maintenance organizations and nursing home residents had an advance directive (Hopp, 2000; Gordon and Shade, 1999; Terry and Zweig, 1994; Levin *et al.* 1999). Approximately 40% of people with HIV infection or a chronic lung condition had an advance directive (Wenger *et al.* 2001; Heffner *et al.* 1996) and 56% of people in the terminal stages of cancer had an advance directive. (Virmani *et al.* 1994). Finally, a retrospective study of decedents showed that, at the time of their death, over 50% had an advance directive; up to 63% among deceased nursing home residents and 75% among hospice residents (Jacobson *et al.* 1996). Apparently people are more likely to formulate an advance directive when they think it more likely that they will need one.

Predisposing, enabling and need factors

Several studies have attempted to identify factors associated with the formulation of advance directives, in order to achieve better understanding of the people who have advance directives and those who do not, and to find opportunities to increase their use. We will arrange these factors according to the three following components: *predisposing*, *enabling* and *need* factors. These components were originally proposed by Andersen and Newman in 1973 as a framework for access to medical care, but have proven useful as a framework for factors associated with the formulation of advance directives (Rosnick and Reynolds, 2003). Predisposing factors are demographic fac-

tors (e.g. age, gender) and factors concerning beliefs (e.g. religion, attitudes). Enabling factors could facilitate access to health care, or in this case more specifically the formulation of advance directives (e.g. education, social support). Need factors are health-related factors, either evaluated or self-perceived, that could motivate someone to access health care or formulate an advance directive. Many *predisposing factors* were found to be associated with the formulation of advance directives in one or more studies, such as: being older, being female, being white, coming from a rural area, being more religious, and not being married (Bravo *et al.* 2003; Phipps *et al.* 2003; Rosnick and Reynolds, 2003; Hopp, 2000; Jacobson *et al.* 1996; Gordon and Shade, 1999; Terry and Zweig, 1994; DeLuca Havens, 2000; Buchanan *et al.* 2004; Elpern *et al.* 1993; Wenger *et al.* 2001; Bradley *et al.* 1998). *Enabling factors* that were found to be associated with having formulated an advance directive were: higher education, higher socio-economic status, higher income, and higher social support (Rosnick and Reynolds, 2003; Hopp, 2000; Ott, 1999; Wenger *et al.* 2001; Bradley *et al.* 1998). *Need factors* that were found to be associated with having formulated an advance directive were: worse (self-perceived) health status, and residing in a nursing home or hospice (Jacobson *et al.* 1996; Elpern *et al.* 1993). Furthermore, several negative *experiences* were associated with having formulated an advance directive: death or illness of a loved one, and negative life-events in general (Inman, 2002; Rosnick and Reynolds, 2003; DeLuca Havens, 2000; Bradley *et al.* 1998). We will classify these factors as need factors, since they are experiences that could influence the perceived need to formulate an advance directive.

Europe vs the USA

In comparison with all the attention that advance directives have received in the USA, the subject is very much underexposed in Europe. This may be because physicians in the USA are more likely to choose more aggressive treatment options than physicians in various European countries (Koeck *et al.* 1998; Alemayehu *et al.* 1991; McKenzie *et al.* 1998). In this context, advance directives, which usually limit treatment, may be considered more necessary in the USA.

In the Netherlands, we have advance directives that are similar to those in the USA, i.e. living wills and people can appoint a representative. People can formulate any advance directive, regardless of their current health condition. Several Dutch associations have issued standard forms which people can complete by marking situations in which they would want the advance directive to apply (e.g. in case of being comatose for a certain number of weeks) and/or treatments which they would want to be provided or forgone in some or all situations (e.g. artificial nutrition and hydration). People can also write an advance directive in their own words, and such a directive can have equal legal value. Considerable attention has recently been paid to the right of patients to refuse treatment. According to the Dutch constitution, this right has always existed, but it has been described in more detail in the Medical Treatment Contract Act, that came into force in 1995. In the Netherlands we recognize a type of living will that does not exist in most other countries, the 'advance euthanasia directive', in which people can request euthanasia in specific situations of incompetence. Since 2002, such requests can legally be granted if the official requirements of due care for euthanasia or assisted suicide (EAS) are met. However, there is much debate in the Netherlands about whether or not in the case of EAS these requirements can *ever* be met, because one of the requirements is that the patient's suffering is unbearable, which is usually considered to be impossible if a patient is comatose or demented, or is considered to be incompetent for another reason. All cases of EAS have to be reported to review committees, and there have been no reports of cases in which the physician performed EAS on the basis of an advance euthanasia directive.

Aim of this study

The aim of this study is to investigate the prevalence of advance directives in the Netherlands and to determine which factors are associated with the formulation of advance directives. Almost no data are available on the prevalence of advance directives in Europe. Especially in the Netherlands, where people can have advance directives concerning euthanasia besides other types of advance

directives, evidence is needed to see how many people have advance directives, how often these concern euthanasia, and whether the same factors influence whether people have an advance directive, in spite of the differences between advance directives in the USA and in the Netherlands. The prevalence will be analyzed in three study groups: the general population up to 60 years of age, the general population over 60 years of age, and the relatives of patients who have died after EAS. These relatives were included because we thought that they were more likely than the general population to have advance directives, and to have informed their physician, as a result of their experience with EAS. We hypothesize that older people are more likely to have advance directives than younger people, since we expect that people with a greater (perceived) risk of needing an advance directive will be more likely to have formulated one. We will also investigate the association between confidence that a physician will respect end-of-life preferences, and the formulation of advance directives, an association not taken into account previously. This seems a relevant factor, because people who are not confident that physicians will respect their end-of-life preferences may attach more importance to the formulation of ADs. Furthermore, in the sample of the population over 60 years of age, we will evaluate several characteristics that were found to be associated with the formulation of advance directives in the studies in the USA. We expect that each of the three types of factors, predisposing, enabling and need, are associated with the formulation of an advance directive, with a decisive role for need factors. By evaluating the factors associated with the formulation of an advance directive, it may be possible to find suggestions to stimulate the formulation of advance directives.

METHODS

Definitions

Advance Directive (AD): A living will or appointment of a health care proxy.

Euthanasia or assisted suicide (EAS): Euthanasia is defined as the administration of drugs by a physician with the explicit intention of ending a patient's life at his/her explicit request, and assisted suicide is defined as the prescription or supply of drugs by a physician with the explicit intention to enable a patient to end his/her own life at his/her explicit request.

General population up to 60 years of age

In September 2002, 1,051 people who were between 20 and 60 years of age completed a postal questionnaire. They were participants in an existing consumer panel randomly selected from the Dutch population by the Netherlands Institute for Health Services Research (NIVEL), designed to be representative of the population of the Netherlands. The only divergence was that women were over-represented in the panel (66%). The response was 78%.

Only the people in this sample who did not have a living will were asked why they did not have one, and what they had talked about if they had ever discussed medical end-of-life treatment with a physician.

Possible determinants of the formulation of an AD available in this sample were age, gender, religious beliefs, level of education, experience with requests for EAS in their environment, self-reported health status (5-point scale) and type of household (from which we extracted 'having a partner' and 'having children' for analyses).

General population over 60 years of age

Data were obtained from the 'Longitudinal Aging Study Amsterdam' (LASA) cohort, a stratified sample of 3107 people who were aged 55—85 in 1992. The sampling method has been described in detail elsewhere (Deeg *et al.* 1998). These subjects are interviewed every three years. In '98—'99, 1874 people who were between 61 and 92 years of age were interviewed face-to-face. Of the original sample of 3,107 people, 760 had died, 30 could not be contacted, 160 were unwilling to participate, 81 were unable to participate as a result of cognitive or physical impairment, and 202 were only available for a shorter telephone interview. Most of the data presented in this article were derived from the 1998 interviews, because extra information concerning advance directives was obtained in this year.

For this sample, in particular, many possible determinants for the formulation of an AD are available. These data do not only concern socio-demographic characteristics but also health characteristics, such as chronic illnesses, functional limitations, and recent hospital visits.

Surviving relatives interview study

Relatives of patients who had died after EAS were interviewed. The relatives were selected through a sample of 167 physicians who had reported EAS to a regional review committee in 2001 or 2002. The sample of physicians was stratified according to specialty, and consisted of clinical specialists (34%), general practitioners (49%) and nursing home physicians (16%). The response rate of the physicians was 92%. These physicians were asked to contact one of the relatives who had been most closely involved in caring for the patients, and to ask them whether they would be willing to be interviewed. Of these 167 physicians, 8 were unwilling to contact a relative because they did not want to burden him/her, 16 were unable to contact a relative, and 46 did not contact a relative but gave no explicit reason. Of the 97 relatives (58%) who were contacted, 3 were unwilling to be interviewed because of lack of time, and 7 said that it was too difficult for them to talk about the deceased. A total of 87 (90%) relatives agreed to be interviewed face-to-face. The average age of the relatives was 58 years (ranging from 29 years to 90 years) and 59% were female. Possible determinants for the formulation of an AD were age, gender, religious beliefs, level of education and type of insurance.

Measurement instruments

To simplify the interpretation of the results of this study, continuous variables were subdivided into classes, using recommended cut-off points if available. We checked that this did not affect the significance of associations. All measurements apply to the sample of 60 years and older, with the exception of religion and education, which also apply to the sample of people up to 60 years of age.

Urbanization

The Statistics Netherlands established an urbanization typology of Dutch municipalities in 1971. They based this typology on three indicators: the percentage of male farmers in the working population, the number of residents in the largest residential area and the proportion of native versus non-native or commuter residents. We dichotomised this typology to distinguish between residents of rural areas and residents of urbanized areas.

Religion

People were asked if they considered themselves to be part of a religious group or connected to a 'philosophy of life'.

Education and income

The highest level of education attained by the respondents was divided into two categories: 'lower education' (elementary not completed, elementary, lower vocational) and 'higher education' (general intermediate, intermediate vocational, general secondary, higher vocational, college, university). These same categories were used in the sample of people up to 60 years of age.

The income was the total monthly net income in the household in Dutch Guilders (2.2 Dfl = 1 Euro ≈ 1.3 US Dollar)

Network size and loneliness

Seven domains of network members were identified, by means of an adaptation of a procedure developed by Cochran *et al*. 1990. The criteria according to which network members were identified were: people (over 18 years of age) with whom the respondent was in touch regularly and who were important to him/her. Networks with up to 12 members were defined as 'small', and networks with 13 or more members were defined as 'large'.

Loneliness was assessed according to a scale developed by De Jong-Gierveld and Kamphuis (1985). The model was based on the so-called cognitive theoretical approach to loneliness. Characteristic of this approach is the emphasis on the discrepancy between what one wants in terms of interpersonal affection and intimacy, and what one has; the greater the discrepancy, the greater the loneliness. A loneliness score (0—11) was computed from eleven items, which were dichotomised as not lonely (0—2) and moderately lonely/very lonely/extremely lonely (3—11).

Chronic illnesses

The number of chronic illnesses was determined by counting the number of diseases or illnesses people had at the time of the interview, which at least endured for three months or for which people needed medical treatment or regular checking for a long time.

Functional limitations and receiving help

As an indicator of physical functioning the respondents were asked if they had difficulty performing three normal activities: going up and down a staircase of 15 steps without having to stop, using their own or public transport, and cutting their own toenails (McWhinnie, 1981). If they had difficulties with at least one of these three activities they were considered to have functional limitations.

The respondents were also asked whether they received help with their personal care. Personal care was defined as one of the following activities: washing, bathing or showering, dressing or undressing, going to the toilet, getting up and sitting down. Furthermore they were asked if the personal care they received was sufficient.

Depressive symptoms and anxiety

Depressive symptoms were measured according to the Dutch version of the 20-item CESD-scale (Radloff, 1977), with the recommended cut-off between 15 and 16. Anxiety was measured according to the 7-item HADS-A scale (Zigmond and Snaith, 1983), the recommended cut-off between 6 and 7.

Cognitive impairment

The MMSE was used to measure cognitive impairment (Folstein *et al.* 1975). A lower score is an indication of greater cognitive impairment. The cut-off point was set at 23/24.

Life-events

A score for negative life-events was composed as previously described by De Beurs *et al.* 2001. The scale was adapted from the inventory developed by Tennant and Andrews (1976). Using data from both the ´95—´96 interview and the ´98—´99 interview, a specific score was added to the total score for each of the following items that had occurred in the past three years: illness or death of partner or close family, divorce, loss of a job, decline in income, having been a victim of a crime, moving house, cognitive decline, deterioration of vision, deterioration of hearing, and increase in the number of chronic illnesses. This led to a total score ranging from 0 to 200, with a cut-off at 100/101.

Analysis

We decided to limit ourselves to the most relevant analysis: we present the prevalence of advance directives in the three measured groups, and a bivariate analysis of the associations between predisposing, enabling and need factors and the formulation of an AD in the general population. For dichotomous factors the relative risk and 95% confidence intervals were calculated, and for the ordinal factors a Mantel-Haenszel Chi-square test was performed. Subsequently, all significant factors were included in a multivariate analysis of the determinants of the probability that older people had an AD. All factors were dichotomous, with the exception of age, income, self-perceived health, and number of chronic illnesses. Stepwise backward logistic regression was applied, removing variables with the highest p-value until each factor in the model was significantly associated with the dependent variable according to 95% confidence intervals. We checked for confounders and found none. We checked for possible interactions in the multivariate model, and added an interaction between religious beliefs and urbanization. Forward logistic regression revealed the same model as the backward regression analysis.

RESULTS

Prevalence of advance directives

Table 1 shows the prevalence of advance directives and several associated issues in younger people (20—60 years), older people (61—92 years), and relatives of patients who died after EAS. Of the older people, 10% had a living will. Most of them had an AD concerning euthanasia (6%); other types of living wills occurred also, but less frequent (2% or less for each type). In comparison with older people, younger people less often had living wills (3%). The reasons younger people most frequently mentioned for not having a

living will were: "never thought about it" (46%), "didn't get round to it" (32%), "not sure what I want"(10%), and "don't think it's necessary"(10%). In comparison with the general population, relatives of a person who had died after EAS more often had living wills (23%).

Whereas older people had most often informed their children about their living will (72%), younger people had most often informed their partner (59%). Relatives of a patient who had died after EAS had frequently informed their general practitioner (75%) and/or their children (70%).

Table 1 Prevalence with 95% confidence intervals (CI) of formulating an advance directive concerning end-of-life care and confidence that the physician will respect such wishes at the end of life (one or more answers possible for each question)*

	20–60 years		61–92 years		Relatives of EAS patients	
	n=1051		*n*=1874		*n*=87	
	%	95% CI	%	95% CI	%	95% CI
Living will	8 missing		16 missing			
No living will	97	(96–98)	90	(89–92)	77	(67–85)
Advance euthanasia directives	2	(1–3)	6	(5–8)	23	(15–83)
DNR (Do Not Resuscitate) order	1	(0–2)	2	(1–2)	3	(1–10)
Description which treatments should be forgone	1	(0–1)	2	(1–3)	6	(2–13)
Other type of living will	1	(0–1)	2	(2–3)	0	(0–4)
Authorized a representative for health care	7 missing		18 missing			
No	72	(69–75)	74	(72–76)	71	(61–81)
Yes, verbally authorized someone	26	(23–28)	19	(17–21)	22	(14–32)
Yes, authorized someone in writing (and verbally)	3	(2–4)	7	(6–8)	7	(3–14)
Who know(s) about the living will?	*n*=31 (2 missing)		*n*=181 (4 missing)		*n*=20	
Partner	59	(39–77)	49	(41–56)	10	(1–32)
Children	34	(18–54)	72	(65–78)	70	(46–88)
General practitioner	45	(26–64)	50	(42–57)	75	(51–91)
Other	41	(24–61)	24	(18–31)	40	(19–64)
Advance care-planning	2 missing		16 missing			
No	98	(97–99)	93	(91–94)	80	(71–88)
Yes	2	(1–3)	7	(6–9)	20	(12–29)
How confident that physician will respect end-of-life wishes	5 missing		14 missing			
Very confident	10	(8–12)	25	(23–27)	32	(23–43)
Quite confident	48	(45–51)	48	(46–50)	46	(35–57)
Not very confident	19	(16–21)	15	(13–17)	11	(6–20)
Not at all confident	1	(1–2)	4	(3–5)	2	(0–8)
Don't know	22	(20–25)	8	(7–9)	8	(3–16)

**Living will*: "Do you have a written document in which it is stated what medical treatment you would or would not like to receive at the end of your life?"
Authorized a representative for health care: "Have you authorized someone, in writing or verbally, to make decisions for you if you are no longer able to do so?"
Advance care-planning: "Have you ever talked to a physician about medical treatment at the end of your life?"
How confident that physician will respect end-of-life wishes: "How confident are you that the physician will respect your wishes concerning medical treatment at the end of your life?"
EAS=euthanasia or assisted suicide.

The prevalence of the appointment of a health care proxy was higher than that of living wills: in each sample between 26% and 29% had authorized someone, verbally or in writing, to make decisions for them if they were no longer able to do so themselves. Among both younger and older people, 29% had either a living will or a appointed a representative. Among the older people, 7% had at some time talked to a physician about medical treatment at the end of their life; younger people had done this less often (2%), and relatives of a person who had died after EAS had done so more often (20%). In most cases the younger people had discussed a wish for euthanasia in specific circumstances. The majority of people in all groups were quite confident to very confident that the physician would respect their wishes concerning medical end-of-life treatment, but the younger people were less confident (58%) than the older people (73%) and the relatives of people who had died after EAS (79%).

Determinants of formulating an advance directive

Table 2 shows the association between several predisposing, enabling and need factors and the formulation of an AD (a living will or the appointment of a health care proxy) in younger people (20—60 years of age) and in older people (61—92 years of age). Of the demographic *predisposing factors*, female gender is associated with an AD in both groups. In older people, a higher age and living in a more urbanized area was also associated with an AD. Whereas younger people *with* a partner were more likely to have an AD, older people *without* a partner were more likely to have an AD. Of the predisposing factors concerning beliefs, not having religious beliefs and having less confidence that the physician would respect wishes concerning medical end-of-life treatment were both associated with an AD in older people. The *enabling factor* of higher education was associated with an AD in both groups, but this was only significant in older people. The *need factor* of a worse self-perceived health status was significantly associated with an AD in both groups. People who had experience with EAS in their environment were significantly more likely to have an AD than those who had no such experience.

Table 3 shows the association between further characteristics of older people (61—92 years of age) and the presence of an AD. The *enabling factors* of income and network size were not significantly associated with an AD. We have discerned three types of *need factors*: evaluated health problems, self-perceived health problems and experiences that could influence perceived need. *Evaluated health problems* that were significantly associated with an AD were: a higher number of chronic illnesses, functional limitations, contact with a medical specialist and hospitalization in the past 6 months, and more depressive/anxiety symptoms. People who were assessed as less cognitively impaired (according to the MMSE score) more often had an AD, but this was not significant. The opposite trend was found in the *perceived health problems*. People who thought that they had memory problems more often had an AD, but this was only significant if they had also consulted a doctor for these perceived memory problems. Experiences that were significantly associated with an AD were: more negative life-events in the past three years, death of a marital partner, and perceived insufficient help with personal care, such as washing, dressing, and going to the toilet.

Table 2 Effect of several characteristics on the formulation of an advance directive concerning end-of-life medical treatments in the form of a written document or a representative (AD=advance directive; RR= relative risk; CI=confidence interval; N.S.=not significant; S.=significant)

Factors		General population (=<60 years)			General population (>60 years)		
		N	Have an AD (row%)	RR (95%CI) Significance	N	Have an AD (row%)	RR (95%CI) Significance
Predisposing (demographic)							
Age (years)	53—60yrs 86—92yrs	174	29	Chi-square	180	37	Chi-square
	45—52yrs 81—85yrs	187	34	linear association	258	34	linear association
	37—44yrs 76—80yrs	261	26	*p*=0.52	283	34	*p*=0.00
	29—36yrs 71—75yrs	288	27	N.S.	351	30	**S.**
	20—28yrs 66—70yrs	141	30		390	26	
	61—65yrs				389	21	
Gender	Female	691	31	**1.24(1.00—1.53)**	1017	33	**1.32(1.13—1.52)**
	Male	360	25	**S.**	834	25	**S.**
Urbanization	High urbanization	—	—	—	1094	35	**1.62(1.39—1.91)**
	Low urbanization	—	—	—	757	21	**S.**
Ethnic identification	Dutch	—	—	—	1831	29	0.73(0.42—1.25)
	Other	—	—	—	20	40	
Partner	No partner	195	21	**0.68(0.51—0.91)**	726	36	**1.47(1.27—1.69)**
	Partner	840	31	**S.**	1125	25	**S.**
Children	No children	433	31	1.12(0.92—1.35)	193	31	1.06(0.84—1.32)
	Children	602	28	N.S.	1658	29	N.S.
Predisposing (beliefs)							
Religion	No religious beliefs	506	31	1.17(0.97—1.41)	669	39	**1.67(1.45—1.92)**
	Religious beliefs	536	27	N.S.	1182	23	**S.**
Confidence in physicians	Not (very) confident	210	37	1.17(0.94—1.45)	357	38	**1.42(1.21—1.66)**
	Quite/very confident	605	31	N.S.	1352	27	**S.**
Enabling							
Education	High education	864	30	1.25(0.95—1.66)	751	34	**1.33(1.16—1.54)**
	Low education	180	24	N.S.	1099	26	**S.**
Need (perceived health problems)							
Self-perceived health	Excellent	183	29	*Chi-square*	188	23	Chi-square
	Good	647	27	linear association	987	28	linear association
	Fair	128	34	***p*=0.04**	468	32	***p*=0.00**
	Good/bad (differs)	76	37	**S.**	167	35	**S.**
	Poor	17	41		41	37	
Need (experiences that could influence perceived need)							
Experience with EAS	Yes	270	40	**1.59(1.31—1.92)**	—	—	—
	No	770	25	**S.**	—	—	—

Table 3 Effect of further psychosocial and health characteristics of people aged 60 years and older on having ADs (advance directives) concerning medical treatments at the end of life (AD=advance directive; RR= relative risk; CI=confidence interval; N.S.=not significant; S.=significant)

		General population (>60 years)			
		N	Have an AD (row%)	RR (95%CI)	Significance
Enabling					
Income (monthly in Dfl)*	Dfl 1000—2000	460	29	Chi-square	N.S.
	Dfl 2001—3000	535	29	linear association	
	Dfl 3001—4000	279	29	*p*=0.26	
	Dfl >4000	359	33		
Network size	Small (0—12)	832	30	1.04(0.90—1.20)	N.S.
	Large (13—62)	884	29		
Need (evaluated health problems)					
Number of chronic	0	269	23	Chi-square	**S.**
illnesses	1	491	28	linear association	
	2	530	28	***p*=0.00**	
	3	327	32		
	4	153	34		
	5—8	81	43		
Functional limitations	Yes	1000	32	**1.24(1.07—1.43)**	**S.**
	No	819	26		
Contact with medical	Yes	911	33	**1.29(1.11—1.49)**	**S.**
specialist in past 6 months	No	930	26		
Hospitalization in past	Yes	162	36	**1.25(1.01—1.56)**	**S.**
6 months	No	1680	29		
Depressive symptoms	High	318	35	**1.26(1.06—1.49)**	**S.**
CES-D Cut-off 15/16	Low	1521	28		
Anxiety	High	225	36	**1.29(1.07—1.56)**	**S.**
HADS-A Cut-off 6/7	Low	1621	28		
Cognitive impairment	High MMSE score	1664	30	1.22(0.94—1.59)	N.S.
MMSE Cut-off 23/24	Low MMSE score	185	24		

* 2.2 Dfl = 1 Euro ≈ 1.3 US Dollar

Table 3 continued (AD=advance directive; RR= relative risk; CI=confidence interval; N.S.=not significant; S.=significant)

		General population (>60 years)			
		N	Have an AD (row%)	RR (95%CI)	Significance
Need (perceived health problems)					
Memory problems	Yes	488	32	1.16(1.00–1.36)	N.S.
(self-perceived)	No	1361	28		
Consulted doctor for	Yes	95	39	**1.37(1.05–1.78)**	**S.**
memory problems	No	1754	29		
Need (experiences that could influence perceived need)					
Life-events past 3 years	High score	86	41	**1.41(1.08–1.84)**	**S.**
	Low score	1739	29		
Marital partner died	Yes	624	37	**1.49(1.29–1.71)**	**S.**
	No	1227	25		
Loneliness	Lonely	655	31	1.10(0.95–1.27)	N.S.
	Not lonely	1172	28		
Living situation	Dependent	91	30	1.02(0.74–1.41)	N.S.
	Independent	1760	29		
Receiving help	Yes	146	33	1.14(0.89–1.46))	N.S.
	No	1704	29		
Adequacy of help	(Somewhat) insufficient	242	39	**1.43(1.20–1.71)**	**S.**
(self-perceived)	Sufficient	1544	27		

* 2.2 Dfl = 1 Euro ≈ 1.3 US Dollar

Multivariate analysis of advance directives

A multivariate analysis of the determinants of the probability of older people having an advance directive is presented in Table 4. The following factors were significant in a multivariate analysis: female gender and higher age (demographic predisposing factors), not being religious and having less confidence that the physician will respect wishes concerning medical end-of-life treatment (predisposing factors concerning beliefs), higher education (enabling factor) and contact with a medical specialist in the past 6 months and the death of a marital partner (need factors). The association between being religious and the formulation of an AD was stronger for people who lived in an urbanized area than for people living in a rural area, but both associations were significant. Many need factors and one predisposing factor were found to be significantly associated in a bivariate analysis, and were eliminated in a multivariate analysis, in the following sequence: having a partner, number of chronic illnesses, self-perceived health, consulted a doctor for memory problems, functional limitations, depressive symptoms, hospitalization in the past 6 months, negative life-events, anxiety, and perceived insufficient help with personal care.

Table 4 Multivariate analysis of the determinants of the probability of having an advance directive (*n*=1874, 173 missing cases, have an AD *n*=499, Cox & Snell R square=0.086)

>60	Odds ratio	95% CI
Predisposing (demographic)		
Gender (female)	1.41	1.11–1.79
Higher age		
61–65yrs	1	
66–70yrs	1.31	0.84–2.04
71–75yrs	1.28	0.82–2.00
76–80yrs	1.69	1.10–2.61
81–85yrs	1.86	1.20–2.89
86–90yrs	2.19	1.39–3.43
Predisposing (beliefs)		
Not religious in an urbanized area	2.88	1.35–6.14
Not religious in a rural area	1.54	1.17–2.03
Less confidence in physicians respecting wishes	1.44	1.11–1.86
Enabling		
Education (higher)	1.55	1.24–1.95
Need (evaluated health problems)		
Contacted medical specialist in past 6 months	1.35	1.08–1.69
Need (experiences that could influence perceived need)		
Marital partner died	1.61	1.24–2.09

DISCUSSION

Only 3% of the people in the 20–60 year age-group in the Netherlands had a living will. As could be expected, older people and relatives of a person who had died after EAS more often had a living will (resp. 10% and 23%). The most frequently occurring type of living will, was an advance euthanasia directive. Although the system of ADs in the Netherlands is very different from the system in the USA, many determinants of having ADs were the same. Different types of factors (predisposing, enabling and need factors) were associated with the formulation of an AD.

Predisposing factors

Predisposing factors played an important role in the formulation of an AD. Women, older people, non-religious people —especially those who lived in an urbanized area— and people with less confidence that the physician would respect their end-of-life wishes were more likely to have formulated an AD. Female gender and higher age were also reported to be factors in studies in the USA, as discussed in the Introduction. Having less confidence that the physician would respect end-of-life wishes was a factor that had not previously been tested in relation to ADs. Not being religious and living in a more urbanized area are exact opposite determinants to those found in the USA. This may be due to the difference in the types of ADs. Although both in the USA and in the Netherlands adherence to an AD often has a life-shortening effect, ADs in the USA usually concern the limitation of treatment, which can be consistent with religious beliefs, whereas ADs in the Netherlands mainly express a wish for euthanasia, which is less reconcilable with most religious beliefs. The interaction between urbanization and religious beliefs might be a consequence of people living in rural areas having more strict religious beliefs than people living in urbanized areas.

Enabling factors

People with a higher level of education (enabling factor) were more likely to have formulated an AD. Higher income was not associated with an AD, as it was found to be in a study in the USA (Rosnick and Reynolds, 2003). We had not expected this to be the case, because the association in that study was probably a result of the link between DPAs for health care and DPAs for financial affairs in florida, where the study was performed. This link does not exist in the Netherlands.

Need factors

The only evaluated health problem that was found to be significantly associated with an AD in a multivariate analysis was contact with a medical specialist in the past 6 months. This is an evaluated health problem rather than a perceived health problem, since the health care system in the Netherlands is such that most people only visit medical specialists after they have been referred by a general practitioner who considers such a visit to be necessary. finally, of the experiences that could have influenced the perceived need, death of a marital partner was significantly associated with the formulation of an AD. This is consistent with results in the USA, that illness or death of a loved one or other negative life-events were associated with the formulation of an AD.

Methodological considerations

The LASA cohort was based on a sample that was representative for the Dutch older population in 1992, with oversampling of men and older old to guarantee sufficient older respondents in later phases of the study. Sample attrition might have affected the generalizability of the results of the interviews held in 1998 (Deeg *et al.* 2002). It is also possible that previous interviews have introduced a bias in the LASA sample. finally, a limitation of the present study is that it is based on self-reports.

Conclusions

Few people in the Netherlands have recorded their end-of-life wishes. Most younger people who had not made a living will indicated that they had either never thought about making one or did intend to make one but had not got round to doing so. This is consistent with the findings of studies of perceived barriers in formulating an AD in the USA. A lack of information, procrastination and avoidance were reasons for not formulating an AD (High 1993; Elpern *et al.* 1993). The belief of physicians that ADs are unnecessary for young, healthy patients amplified these barriers (Ott, 1999).

Should the formulation of ADs be further stimulated in the Netherlands? In the USA the importance of ADs has been questioned, because they do not always result in care that is consistent with the patient's preferences (Covinsky *et al.* 2000). Moreover, ADs do not substantially enhance physician-patient communication, and physicians are often not aware that the patient has an AD (Teno *et al.* 1997). However, this does not mean that the formulation of an AD is useless: another study has shown that the willingness of physicians to adhere to directives is dependent on several factors, such as the specificity of the directive, whether or not the directive is supported by a proxy, and whether or not the directive was coupled with a physician-patient discussion (Mower and Baraff, 1993). According to relatives, ADs did seem to limit end-of-life treatment, as well as ease the burden of their decision-making (Jacobson *et al.* 1996).

When people fall seriously ill, they value ADs more. Before their death approximately half of the people in the original LASA sample who died between '95—'96 and '98—'99 had expressed a preference for or against one or more medical end-of-life decisions (Klinkenberg *et al.* 2004). In a study of people with AIDS, only 38% had discussed preferences for life-sustaining care with their physician, but of those who had not, 72% wanted to do so (Haas *et al.* 1993). In a group of patients with a chronic lung condition, only 15% had discussed life-support, although 99% wanted to have patient-physician advance directive discussions (Heffner *et al.* 1996).

In conclusion, as long as healthy or seriously ill people want to have an AD, but have not received enough information and/or stimulation to actually formulate one, further stimulation seems to be warranted. ADs can bring peace of mind after they have been formulated, they can help to limit treatment, and ease the burden of decision-making for family members, also, and maybe in particular, if the situation is unexpected, as in the case of myocardial infarction and accidents. It appears that stimulation to formulate an AD can be achieved relatively easily. The PSDA requires that health care organizations inform their patients about their right to formulate an AD concerning health care. People in the USA were more likely to have an AD if they were admitted to a nursing home after the PSDA (compared with before the PSDA), if they had discussed or had been asked about end-of-life preferences, or had AD educational experiences (Gordon and Shade, 1999; Terry and Zweig, 1994; DeLuca Havens, 2000; Wenger *et al.* 2001; Bradley *et al.* 1998). In the USA, actively providing information about ADs stimulated the formulation of ADs. Can this be achieved in the Netherlands? The present study suggests that it can. Predisposing factors are informative, but do not give suggestions for the stimulation of ADs. Enabling and need factors do. The fact that people with a higher level of education are more likely to formulate an AD, implies that more effort should be made to inform the general population, instead of leaving them to obtain information by themselves. In this way, perhaps, the association between education and ADs can be abolished. The need factors —people are more likely to have formulated an AD if they have recently contacted a medical specialist, and if their marital partner has died— also indicate that the formulation of an AD should be more actively stimulated, because people apparently do not think about ADs until they realize that they might need one. Interventions might most appropriately focus on getting primary care physicians to stimulate formulation of ADs, before any medical condition becomes serious enough to warrant specialist contact.

However, the aim should not be just to stimulate the formulation of ADs, it should also be to stimulate clear and usable ADs. In the Netherlands, most ADs concern euthanasia, and, as we discussed in the Introduction, such ADs are very unlikely to be adhered to. Such a situation, in which most ADs are difficult or impossible to adhere to in actual medical practice, should be prevented by providing those who are interested with adequate information about the different types of ADs and their legal value, and by reformulating standard ADs in order to make them more attuned to practice. For the latter more research into the barriers of following ADs in practice is needed.

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Chapter 6

Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands

"I'm going to hate the day Dad dies, but it's time for him to go."

Michael Reagan

ABSTRACT

Objectives : To estimate the incidence of (compliance with) advance euthanasia directives of patients suffering from dementia in the Netherlands and to gain knowledge about the experiences of physicians.

Methods : Four hundred ten physicians were interviewed retrospectively about their demented patients who had an advance euthanasia directive. Nursing home physicians were interviewed more extensively.

Results : Approximately 2,200 demented patients with an advance euthanasia directive die annually after being treated by a physician who knows about this directive. In 76% of such cases, compliance with the directive was discussed, but euthanasia was seldom performed. In two thirds of the cases of demented nursing home patients with an advance euthanasia directive, the physician was able to identify during the course of the disease a situation for which the patient had intended the directive. One-quarter of the nursing home physicians thought that their most recent patient suffered unbearably to a (very) high degree, and half of them thought that the patient suffered hopelessly to a (very) high degree. In three-quarters of the cases, the relatives did not want the nursing home physician to comply with the directive, but they did want to respect the patient's wishes by forgoing life-prolonging treatment, which occurred in approximately 90% of cases.

Conclusion : Most nursing home physicians think that the suffering of patients with dementia can be unbearable and hopeless as a consequence of dementia, but most physicians do not consider dementia to be grounds for euthanasia, unless perhaps the patient has an additional illness.

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Fifty years after the first conviction in the Netherlands of a physician for ''life-termination on request,'' it became legally permissible for physicians to perform euthanasia under the new euthanasia law that was introduced in 2002 (Court of Amsterdam, 1952; Termination of Life on Request and Assisted Suicide, 2002). Although, under this new law, euthanasia is still subject to the penal code, it is no longer illegal if a physician has reported it to the coroner and has performed it according to the 'requirements of due care.' The first four requirements are the following.

1. The physician is convinced that the patient's request for euthanasia was voluntary and well considered.
2. The physician is convinced that the patient's suffering was unbearable and hopeless.
3. The physician informed the patient about his/her situation and prospects.
4. The physician and the patient were both convinced that there was no other reasonable solution.

Furthermore, the physician had to consult at least one independent physician and to perform the euthanasia according to certain guidelines. These requirements are stipulated in Article 2.1 of the law. Application of these requirements in practice is not difficult, because they have been tried and tested since the first unofficial review procedure in 1991 (van der Wal *et al.* 2003). Article 2.2 concerns patients who are no longer capable of expressing their own wishes (i.e., patients who are comatose or suffer from dementia). According to this Article, physicians are allowed to perform euthanasia for such patients, based on a written request at the time when they were still competent, provided that the requirements of due care are met. Article 2.2 is more difficult to apply in practice, possibly because it was not based on a history of experience, as was the case with Article 2.1. How, for example, should requirements (3) and (4), which concern providing information, communication, and reflection, when a patient is incompetent, be interpreted? Should this be done before the patient becomes incompetent, or can 'a representative' be substituted where the requirements refer to the 'patient'? More fundamental objections can arise with regard to requirement (2) concerning unbearable and hopeless suffering. Unbearable suffering, in particular, is — in the case of competent patients — considered to be a subjective patient experience. Comatose patients are considered to be incapable of such an experience (Payne *et al.* 1996). Article 2.2, focusing on incompetent patients, therefore appears to apply, in particular, to patients with dementia. The new euthanasia legislation — including Article 2.2 — was first proposed in 1998, but whether demented patients can suffer unbearably was already a subject of debate before this new law was first proposed. The Royal Dutch Medical Association (RDMA) was the first organization to take an official position in 1997 (Royal Dutch Medical Association, 1997). In its opinion, a demented patient who has serious symptoms indicating serious suffering can suffer unbearably and hopelessly just like a non-demented patient, and the fact that the patient is demented is important but secondary. This also applies, and in particular, if the serious suffering is a consequence of forgoing treatment, as requested in the advance directive of the patient. The RDMA left unanswered the question of whether the requirements of due care could also be met in the absence of suffering in addition to the dementia. The Dutch Health Council published a similar position statement in 2002 (Health Council of the Netherlands, 2002). The Dutch Association of Nursing Home Physicians (NVVA) also published a position statement concerning this subject in 1997 (Dutch Association of Nursing Home Physicians, 1997). They wanted a more detailed guide for practical use. Their position is that the advance euthanasia directives of patients with advanced dementia should never be complied with because, in the advanced stages of dementia, they can never have enough understanding of their situation to meet the requirement of unbearable suffering. However, the NVVA does not exclude all cases of physician-assisted death. In rare instances, when additional illnesses or complications cannot be satisfactorily treated, and the physician is of the opinion that the patient is in an unacceptable state of suffering as a consequence, physician-assisted death can be ethically acceptable. Advance directives can serve to support such decision-making.

No cases of euthanasia based on the advance directive of a demented patient have yet been reported to the regional review committees or the public prosecutor, but with an estimated notification rate of 54%, this does not mean that euthanasia based on the advance directive of a demented patient does not occur (van der Wal *et al.* 2003). Euthanasia based on written requests has not been studied previously. The aim of this study was to estimate the incidence of (compliance with) advance euthanasia directives of demented patients in the Netherlands, to gain knowledge about the experiences of physicians, and to obtain insight into the opinion of physicians about the applicability of advance euthanasia requests made by demented patients and about the extent of suffering of demented patients.

METHODS

Definitions

An advance euthanasia directive is a written request for euthanasia made by a patient, intended for a situation in which the patient has become incompetent. In this article, compliance with the advance euthanasia directive of a demented patient is defined as the administration of drugs with the explicit intention to hasten the death of the patient at the explicit request of the patient, as stated in the advance euthanasia directive.

Design and study population

This study was performed in 2002 as part of a large-scale study focusing on medical decision-making at the end of life and consisted of retrospective semi-structured interviews with a random sample of nursing home physicians (NHPs) (n=77), general practitioners (GPs) (n=125), and clinical specialists (cardiologists, surgeons, and specialists in internal medicine, pulmonology, and neurology) (n=208) (van der Wal *et al.* 2003; Onwuteaka-Philipsen *et al.* 2003). In the Netherlands, nursing home medicine is a separate medical specialty, and nursing homes employ NHPs after they complete a 2-year specialist training program. To meet the criteria for inclusion in this study, these physicians had to have been practicing in their registered specialty in the same nursing home, practice, or hospital for the previous 2 years. Of the 482 physicians who met the selection criteria, 72 (15%) were unwilling to participate, mostly because of lack of time.

Measurement instruments and analysis

To enable the physicians to feel free to speak about potentially illegal acts, the researchers guaranteed anonymity. Moreover, the Minister of Justice guaranteed that he would not initiate any judicial inquiries based on the information collected in this study.

The interviews, which physicians who had received specific training for this study conducted, had an average duration of 1.5 to 2 hours.

NHPs, GPs, and clinical specialists were asked about their experience with demented patients who had an advance euthanasia directive. They were asked how many of their patients who had died in 2000 or 2001 suffered from dementia and had an advance euthanasia directive and how often they had discussed whether to comply with these euthanasia directives. They were asked with whom and on whose initiative the discussion had been held and whether the patient in question had a serious illness, such as cancer, in addition to the dementia. finally, they were asked whether they had ever complied with the advance euthanasia directive of a demented patient and, if not, whether they thought it conceivable they ever would.

The NHPs were also asked about their most recent case of a demented patient with an advance euthanasia directive who had died. This yielded 40 cases described in detail. The NHPs provided information about characteristics of the patient, the stage of dementia, and the symptoms the patient had. They indicated, using a description of the phases of the Global Deterioration Scale (GDS), which GDS phase best matched the stage of dementia of their patient in the last month before death.

Some questions that the NHPs were asked in the interviews concerned the following issues. Did they think, during the course of the disease, that a situation could be identified for which the patient intended the advance euthanasia directive? What was, in their opinion, the wish of the patient once demented? How important did they consider the wishes of the patient, the relatives, and the

representatives of the patient to be in decisions with regard to forgoing treatment? Did they think that the patient suffered and, if so, to what extent and in what respect?
To calculate estimates that were representative for the Netherlands, the number of cases of (requests for) euthanasia was weighted for the specialty of the physician. The seven specialties included in the sample cover 95%of the deaths in the Netherlands. Each specialty was given a weighting factor according to the number of physicians interviewed in relation to the number of physicians practicing in that specialty. finally, the 5% of deaths covered by physicians other than the seven types included in the study were corrected for.

RESULTS

Physicians experiences with advance euthanasia directives of demented patients

Table 1 shows that 29% of the physicians had treated a patient with dementia who had an advance euthanasia directive, 13% had treated such a patient until death in the previous 2 years, and 9% had discussed whether to comply with the directive in at least one of these cases. The NHPs had experience with these cases more often than other physicians (66%, vs 28% of GPs and 23% of specialists) and had relatively more often discussed whether to comply with the directive (48%, vs 6% of GPs and 8% of specialists). Three percent of the physicians had complied with the advance euthanasia directive of a demented patient, 44% had never done so but thought it conceivable that they might in the future, and 54% had never done so and thought it inconceivable that they ever would. The situations in which the physicians considered it conceivable that they might comply with an advance euthanasia directive mainly contained one or more of the following elements: if the patient suffered unbearably and hopelessly as a consequence of an additional disease (63%), if it was in a very advanced stage of the dementia (21%), if it was legal (20%), if it was in the last phase of life (17%), and if it was in an early stage of the dementia when the patient would still be competent to decide about the treatment (16%).

Table 1 Experiences with and actions around advance euthanasia directives of demented patients

	Nursing home physicians *n*=77	General practitioners *n*=125	Clinical specialists *n*=208	Total* *n*=410
I have treated one or more patients with dementia who had an advance euthanasia directive	66	28	23	29
I have treated one or more patients with dementia who had an advance euthanasia directive until their death in the previous two years	50	10	11	13
I have discussed whether to comply with the advance euthanasia directive of at least one of these patients	48	6	8	9
I have complied with the advance euthanasia directive of one or more demented patients	4	3	1	3
I have never complied with the advance euthanasia directive of a demented patient, but it is conceivable that I might	22	50	38	44
I have never complied with the advance euthanasia directive of a demented patient, and it is not conceivable that I would	74	47	61	54

*Percentages are weighted to make a representative estimate for all physicians in the Netherlands

The most frequently mentioned reasons for thinking it inconceivable that they would ever comply with the advance euthanasia directive of a demented patient were an advance euthanasia directive is not a valid request (37%) and euthanasia for a patient with dementia is unacceptable (32%). The NHPs also often said that it was against nursing home policy (38%).

Incidence of deaths of demented patients with an advance euthanasia directive

In 2000 and 2001, the 410 physicians in the sample treated 114 demented patients with an advance euthanasia directive until they died per year. In 93 cases, compliance with the advance euthanasia directive was discussed, and in five cases, the physician had administered drugs with the explicit intention to hasten the death of the patient. Based on these figures, it can be estimated that, each year, physicians in the Netherlands treated approximately 2,200 (95% confidence interval (CI)=1,700–2,700) demented patients with an advance euthanasia directive until they died. In 1,600 (95% CI=1,200–2,000) cases (76%), compliance with the advance euthanasia directive was discussed, but because the advance euthanasia directive was seldom complied with, it was impossible to make a reliable estimate of the number of times that euthanasia was performed. If compliance with the advance euthanasia directive was discussed, this took place approximately 90% of the time with the patient's relatives or representatives. In the remaining cases, compliance with the advance euthanasia directive was not discussed with the patient's relatives or representatives but only with other physicians, nurses, or other healthcare workers. In the case of demented patients in a hospital, it was usually the relatives or the representatives who took the initiative to discuss the advance euthanasia directive, and in the case of demented patients in a nursing home, it was usually the physician. In the hospital, approximately 80% of the demented patients whose advance euthanasia directive was discussed had a serious illness, such as cancer, in addition to the dementia, and in the nursing home this was the case in approximately 10% of the demented patients.

Patient characteristics

Table 2 presents the characteristics of the 40 patients who were discussed in the interviews. The average age of the patients at death was 83. Most patients (26/39) had a standard advance euthanasia directive as issued by the Dutch Association for Voluntary Euthanasia, indicating the situations in which they wanted euthanasia, and others (12/39) had formulated a personal advance euthanasia directive, sometimes in consultation with their GP. The symptoms that were most often present in any degree at the time when the NHP discussed the advance euthanasia directive with the relatives for the last time before the patient's death were diminished/no familiarity with own past life (39/39), diminished activity (38/39), loss of balance/tendency to fall (36/39) unstable/bedridden (36/39), (partial) loss of verbal communication (35/39), incontinence (35/39), ataxia (32/39), diminished recognition of relatives (31/38), episodes of anxiety (31/39), and loss of appetite (31/39).

Table 2 Characteristics of deceased demented nursing home patients with an advance euthanasia directive (*n*=40)

	n	%		n	%
Gender			**Years since admission to a nursing home till death**		
Male	7	18	<1 year	12	30
Female	33	83	1—5 years	25	63
Type of advance euthanasia directive*			> 5 years	3	8
Personally formulated	12	31	**Additional serious illnesses in the month prior to death**		
Standard	26	67	No	13	32
Other	1	3	Yes	27	68
Representative appointed by the patient*			Pneumonia	9	23
None	13	33	CVA (cerebrovascular accident)	4	10
Partner	4	10	Heart failure	3	8
Child	20	51	Diabetes	3	8
Other	2	5	Cancer	3	8
Primary reason for admission			Other	14	35
Dementia	33	83	**GDS phase prior to death†**		
Other	7	18	3 (mild)	1	3
Years treated by respondent			4 (moderate)	4	10
<1 year	16	40	5 (moderate to severe)	7	18
1—5 years	23	58	6 (severe)	13	33
> 5 years	1	3	7 (very severe)	15	38

*This information was not available for the one case in which whether or not to comply with the advance euthanasia directive was not discussed with the relatives or representatives.
†GDS: Global Deterioration Scale

Applicability of and discussion about advance euthanasia directives

In 26 of 39 cases, the NHP was of the opinion that the patient had experienced states for which the advance euthanasia directive was intended. This applied more often if, in their opinion, the patient's suffering was more severe (Table 3). In the remaining 13 cases, the NHP did not think that the patient had experienced states for which the advance euthanasia directive was intended, because the patient was not suffering unbearably (11/39), the patient's advance euthanasia directive was not specific for the situation (5/39), or for other reasons (4/39). In 39 of the 40 cases, the NHP had discussed with the patient's relatives or representatives whether the advance euthanasia directive should be complied with. The last time that the advance euthanasia directive was discussed, in 21 of the 39 cases, the NHP initiated the discussion; in 14 cases, the relatives or representatives; and in four cases, both parties. If the NHP had initiated the discussion, this was most often because the patient had a serious illness in addition to the dementia (7/25) and most often with the intention to support a restricted treatment policy (14/25). If it was the relatives or representatives who had initiated the discussion, this was most often because of the patient's hopeless suffering (5/18) and most often with the intention to request that the NHP comply with the advance euthanasia directive (8/18).

Table 3 Association between the extent of suffering and whether the nursing home physician thought the patient had experienced states for which the advance euthanasia directive was intended (*n*=39, 1 missing case)

Patient's suffering	Patient had experienced states for which the advance euthanasia directive was intended	
	Yes	No
	n (%)	
Unbearable		
To a very high degree	4 (100)	–
To a high degree	5 (83)	1 (17)
To a lesser degree	11 (79)	3 (21)
Did not	6 (40)	9 (60)
Total	26 (67)	13 (33)
Hopeless		
To a very high degree	15 (100)	–
To a high degree	3 (43)	4 (57)
To a lesser degree	3 (43)	4 (57)
Did not	5 (50)	5 (50)
Total	26 (67)	13 (33)

*Chi-square linear association with extent of suffering p=.00

Unbearable and hopeless suffering

In the opinion of the NHPs, the patient's suffering was unbearable to a very high degree in four of 39 cases, to a high degree in six cases, and to a lesser degree in 14 cases. The other NHPs (15/39) did not think that the patient's suffering was unbearable. NHPs who thought that the patient suffered unbearably (24/39) were asked in what respect(s) the patient suffered. They most often said that the patient suffered from the dementia itself (10/22), meaning from the progressive deterioration (6/22) or that the patient was afraid because he or she did not understand things anymore (3/22), or that the patient did not want to be dependent but was becoming more dependent (2/22). Other causes of unbearable suffering that were mentioned were agitation or confusion (8/22), anxiety (7/22), pain (6/22), cramps or contractures (5/22), difficulty breathing (3/22), pressure ulcers (2/22), vomiting (1/22), and depressed mood (1/22). Even though the dementia itself was most often mentioned as a cause of unbearable suffering, in only 1/10 cases was it associated with a very high degree of suffering. More often associated with a very high degree of suffering were difficulty breathing (2/3), cramps or contractures (2/5), agitation or confusion (3/8), pain (2/6), and anxiety (2/7).

In the opinion of the NHPs, the patient suffered hopelessly to a very high degree in 15 of 39 cases, to a high degree in seven cases, and to a lesser degree also in seven cases. The other NHPs (10/39) did not think that the patient's suffering was hopeless. NHPs who thought that the patient suffered hopelessly (29/39) were asked in what respect(s) the patient suffered. Most of the NHPs said that dementia leads to hopeless suffering because it is progressive and cannot be cured (25/27), and some said that the suffering was hopeless because it would increase (3/27), because the patient's dependency would increase (2/27), or because the patient was unhappy in a nursing home (1/27).

Wishes of the patients and the relatives and the decisions made by the physicians

In answer to the question ''What was, in your opinion, the wish of the patient with regard to euthanasia, at the time when compliance with the advance euthanasia directive was (last) discussed?'' 33 of the 39 NHPs said that they were unable to determine this, four said that they thought that the patient wanted euthanasia, and two thought that the patient did not want euthanasia because they thought that the fears of their patients had not become reality (Table 4).

According to the NHPs, in 10 of 40 cases, the patient's family or representatives wanted them to comply with the advance euthanasia directive; in 29 cases, they did not want this but wanted a restricted policy of treatment; and in one case, they did not express any opinion (Table 4). Of the 40 NHPs, two had decided to comply with the directive, and in both cases the patient suffered severely from an additional serious illness. Both NHPs had intended to hasten the death of the patient but used morphine and not muscle relaxants, which are the standard euthanasia drugs recommended by the Royal Dutch Association for the Advancement of Pharmacy. One NHP doubted whether he had shortened the life of his patient at all. A more detailed description of the other case is given in Appendix 1. In most cases (36/40), a treatment that could have prolonged life was forgone before the patient's death. This most often concerned forgoing tube feeding (18/29), antibiotics (14/29), or hospital admission or surgical intervention (6/29).

NHPs who had forgone treatment were asked whether certain factors had influenced their decision to do so. The medical situation had a strong influence in 26 of 35 cases, the personal attitude of the physician in 20 of 35 cases, and, if present, a serious illness in addition to the dementia (15/22). Factors that less often had a strong influence were the opinion of the representatives if any (9/23), the opinion of the relatives (11/34), and the opinion of the demented patient (12/35). The advance euthanasia directive had a strong influence on the decision to forgo treatment in 11 of 35 cases.

Table 4 (Presumed) wishes of demented patients and wishes of relatives or representatives concerning medical decisions at the end of life at the time of the decision-making, according to the nursing home physician who made the decision (*n*=40)

	(Presumed) wish of the demented patient*		Wishes of relatives or representatives		Decision of the physician	
	n	%	n	%	n	%
Compliance with the advance euthanasia directive	4	10	10	26	2	5
No euthanasia, but foregoing life-prolonging treatment	2	5	29	72	36	90
No euthanasia or foregoing life-prolonging treatment	–	–	–	–	2	5
No opinion	–	–	1	3	–	–
Unable to determine	33	85	–	–	–	–

*This information was not available for the one case in which whether or not to comply with the advance euthanasia directive was not discussed with the relatives or representatives.

DISCUSSION

Patients who become demented often formulate advance euthanasia directives. Even though the requirements of due care with regard to euthanasia could have been met — most NHPs were able to identify a situation for which the patient had intended the directive, and most NHPs thought there was a certain degree of unbearable and hopeless suffering — the directives were seldom complied with. Most physicians thought it inconceivable to comply with the advance euthanasia directive of a demented patient — because they did not regard an advance euthanasia directive as a valid request or because they considered euthanasia for a patient with dementia to be unacceptable.

Incidence of (compliance with) advance euthanasia directives of demented patients

In the Netherlands, approximately 2,200 demented patients die annually who, by report of their physician, had completed an advance euthanasia directive. This may be an underestimate of the true rate because physicians may not always know about the existence of advance directives, especially if the family opposes euthanasia or does not bring the directive's existence to the attention of the physician.

In most cases, the question of whether to comply with the advance euthanasia directive of a demented patient was discussed with the patient's relatives or representatives, but euthanasia was seldom performed. If the NHP complied with the advance euthanasia directive, the patient also suffered from an additional illness and had symptoms indicating serious suffering. In these cases, the NHPs did not use the recommended euthanasia drugs, and they did not report to the regional review committees or the public prosecutor. These NHPs administered drugs with the explicit intention of hastening the death of the patient, but it is uncertain whether they indeed did so.

Physicians' experiences with advance euthanasia directives

In as many as two-thirds of the cases of demented patients with an advance euthanasia directive, the NHP was able to identify in the course of the patient's disease a state for which the previously competent patient had intended the directive, in the opinion of the NHP. However, NHPs mentioned the advance euthanasia directive most often to support decisions to forgo treatment. Sometimes the relatives or representatives explicitly asked the NHP to comply with the advance euthanasia directive, but in most cases they only came to an agreement to take the advance euthanasia directive into account in making decisions to forgo life-prolonging treatments. In the Netherlands, advance directives are also formulated with regard to forgoing treatment, and since 1995, they are explicitly binding for physicians, unless they have well-founded reasons not to comply (Medical Treatment Contract Act, 1995). Perhaps because some directives with regard to forgoing treatment can be interpreted in various ways, advance euthanasia directives are sometimes used to support a decision to forgo treatment. For 53% of all patients in Dutch nursing homes, a decision to forgo treatment is made before their death (van der Heide *et al.* 1997). This percentage may well be higher for patients with dementia but probably not as high as the 90% that was found for demented patients with an advance euthanasia directive in the present study. Whether this high percentage should be attributed to the presence of the advance euthanasia directive or to other factors cannot be established on the basis of the results of the present study.

Suffering of demented patients

One of the requirements of due care of euthanasia is that the patient's suffering be unbearable and hopeless, but there is no consensus about the extent of the suffering of demented patients. Most physicians do not consider dementia as grounds for euthanasia in itself, but they sometimes think that it could be if a demented patient with an advance euthanasia directive suffers unbearably and

hopelessly from an additional illness. That seems to be in accordance with the position statements of the Health Council, the RDMA, and the NVVA, as discussed above.

The NHPs thought that their most recent patient with dementia suffered unbearably and hopelessly to some degree in 62% and 74% of cases, respectively, and to a (very) high degree in 26% and 56% of cases, respectively. This is far more than the rare instances the NVVA had anticipated. The NVVA seems to be correct in explicitly mentioning complications of dementia as a source of suffering, and not only ''additional illness,'' which can be interpreted literally as meaning only comorbidity or, more freely, as any illness in addition to the cognitive decline of the dementia. According to the NHPs in this study, the suffering was almost exclusively a result of dementia and its complications and not of an additional illness.

Box 1 Description of a case in which a nursing home physician (nhp) complied with the advance euthanasia directive of a woman with vascular dementia

The patient was a woman in her 80s with a vascular disorder, serious contractures, and pressure ulcers. She had been in the nursing home for several years and suffered from advanced vascular dementia. She had drawn up an advance euthanasia directive with the help of her general practitioner. In this advance euthanasia directive, she specified being unable to decide for herself and being in a permanent vegetative state as reasons for wanting euthanasia. She had also appointed her daughter as her representative. When her symptoms increased, the NHP and her daughter were convinced that she suffered unbearably from severe pain and fears. The NHP gave her medication to suppress the symptoms, but the daughter thought that the suffering lasted too long and asked the physician to comply with the advance euthanasia directive. The NHP gave 120 mg intramuscular morphine and 60 mg subcutaneous Valium. He thought that he had shortened the life of his patient by a week at the most.

Non-compliance with advance euthanasia directives

The most frequently mentioned reasons why NHPs think it inconceivable that they would ever comply with the advance euthanasia directive of a demented patient were that, for patients with dementia, an advance euthanasia directive is not a valid request, it is against the nursing home policy, and euthanasia for a patient with dementia is unacceptable. The argument that an advance euthanasia directive is not a valid request can be interpreted as the argument that a demented person becomes a psychologically different person and that therefore the previously competent person does not have the right to decide about the currently demented person (Dresser and Robertson, 1989; Dresser, 1995; Robertson, 1991). It can also be interpreted as a more simple objection — that the advance directive was formulated at a time when the exact situation in which they would be used was not known, and therefore it is not certain that the patient would really want what is specified in the directive because he or she was unaware of the eventual situation (Crippen *et al.* 2000; Berghmans, 2000). The other argument, that euthanasia for a patient with dementia is unacceptable, can be based on these same arguments, but it can also be based on religious beliefs or a more general philosophy of life.

There is general consensus that requests to forgo treatment should in principle be honored in the case of demented patients, in spite of all the above-mentioned counterarguments and even when a patient is ''pleasantly demented'' (Berghmans, 1997). Physicians are not obliged to comply with requests for euthanasia, as they are with requests to forgo treatment, but it would not be implausible to assume that most people in the Netherlands are not aware of this distinction. Therefore, it would not be unreasonable to assess and evaluate all well-considered requests for euthanasia according to the requirements of due care, even though these requirements only legally apply when requests are granted. Because it is legally possible to grant written requests for euthanasia made by demented patients, it would be appropriate to develop guidelines that assist physicians in their decision-making and in their communication with the relatives of these patients.

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Chapter 7

Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia

"As Christians who trust in the promise of eternal life, we recognize that death does not have the final word. Accordingly, we need not always prevent death until the last possible moment; but we should never intentionally cause death or abandon the dying person as though he or she were unworthy of respect."

Nutrition & Hydration: Moral and Pastoral Reflections- National Conference of Catholic Bishops (United States) 1992

ABSTRACT

Objective : For many nursing home patients in the advanced stages of dementia, a decision to start or forgo treatment has to be taken at the end of their life. It is very important for the peace of mind of all involved in such decision-making that there is agreement on which decision is in the best interest of the patient. It is thus important to investigate the attitude of physicians, nurses and relatives towards medical end-of-life decisions concerning patients with dementia, so that the policy in nursing homes can be tuned to stimulate dialogue and understanding between all parties.

Methods : Fifteen statements about artificial nutrition and hydration (ANH), advance directives, hastening death, self-determination and euthanasia, and nursing home policy were presented to physicians, nurses and relatives of nursing home patients suffering from dementia.

Results : In general, physicians, nurses and relatives agree on many aspects of end-of-life decision-making for nursing home patients with dementia. However, on some issues the outcomes of the decision-making may differ. Relatives attach more importance to advance directives than physicians, and have more permissive attitudes towards hastening death.

Conclusion : Although physicians, nurses and relatives are all guided by the best interest of the patient, it seems that differences in religious beliefs, perspective of the patient, and responsibility can lead to different attitudes towards end-of-life decisions.

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Dementia mainly affects very old people, and as the number of very old people is increasing worldwide, the number of people suffering from dementia is also increasing worldwide (Wimo *et al.* 2003). In the Netherlands, 1 in every 93 people suffered from dementia in 2000, and this is estimated to increase to 1 in 44 in 2050. In 2000, 35% of the people suffering from dementia in the Netherlands were residing in a nursing home or in a home for the aged (Health Council of the Netherlands, 2002).

Dementia is a progressive disease that is ultimately fatal. For 53% of all patients in Dutch nursing homes an explicit decision to forgo treatment is made prior to their death (van der Heide *et al.* 1997). This percentage is probably even higher for patients with dementia (Onwuteaka-Philipsen *et al.* 2001). Such decisions can concern forgoing treatment in the case of intercurrent diseases or, late in the course of the dementia, forgoing artificial nutrition and hydration (ANH) if the patient no longer takes in enough food and fluids to sustain life. ANH can be administered through a nasogastric tube or a percutaneous endoscopic gastrostomy tube (PEG tube). It is also possible to provide only fluids through a hypodermoclyse or an intravenous infusion.

Decisions to forgo treatment can be difficult to make, since most patients with dementia are no longer able to make these decisions for themselves. Close relatives and physicians, sometimes in dialogue with other relatives and nurses, will therefore have to make these decisions for the patient. Most nursing home physicians strive to reach agreement with family and nurses which decision is in the best interest of the patient, but the nursing home physician has the greatest influence on the decision-making (Pasman *et al.* 2004). It is very important for the peace of mind of all involved that there is agreement on which decision is in the best interest of the patient (Kirchhoff *et al.* 2002).

It is thus important to investigate the attitude of physicians, nurses and relatives towards medical end-of-life decisions concerning patients with dementia, so that the policy in nursing homes can be tuned to stimulate dialogue and understanding between all parties.

In this study, 15 statements about ANH, advance directives, hastening death, self-determination and euthanasia, and nursing home policy were presented to physicians, nurses and relatives of nursing home patients suffering from dementia for whom a decision concerning ANH was made. We compared the results of the three groups and investigated factors that could influence attitude towards these statements.

METHODS

Design and data collection

The current study is part of an observational study, based on written questionnaires completed by physicians, nurses and relatives of nursing home patients suffering from dementia for whom a decision concerning ANH was made. In the Netherlands, nursing home medicine is a separate medical specialty, and nursing home physicians are employed by the nursing home. Since 1990, they can follow a two-year specialist training programme (Hoek *et al.* 2000). Three regions in the Netherlands were selected as being representative with regard to urbanisation and secularity, and 70 nursing homes from these regions were invited to participate in this study. In the two smaller regions, all nursing homes were contacted (24 in Limburg, and 22 in Overijssel) and in one larger region about half of the nursing homes was contacted (24 in Noord-Holland). Of these nursing homes, 39 agreed to participate. Reasons given by the management of the nursing homes which were unwilling to participate were heavy workload and/or shortage of personnel (14 nursing homes), already participating in other studies (7 nursing homes), reorganization (4 nursing homes), or no specific reason (6 nursing homes).

The primary objective of the main study was to investigate decisions concerning ANH in patients in the advanced stages of dementia (Pasman *et al.* 2004). Physicians in the nursing homes were asked to include patients who met the following criteria: 1) the patient was on a psycho-geriatric ward, and 2) a decision concerning ANH had to be taken because the patient did not take in enough fluids to sustain life (in the opinion of the physician). The patients were included and the data were collected in 2000. The physicians who participated in our study completed a

questionnaire at baseline (response 107/112=96%). If a physician included a patient in the study, a member of the nursing staff involved in the decision-making for this patient and a relative of the patient were asked to complete a questionnaire on the day on which the decision concerning ANH was made, after the decision-making process was completed. In total, 190 patients were included by 75 physicians from 32 nursing homes. A total of 136 relatives completed a questionnaire (response 72%), and 178 nurses who were involved in the decision-making also completed a questionnaire (response 94%).

The questionnaires for the physicians and nurses contained 15 statements that were related to end-of-life decisions concerning nursing home patients with dementia. These statements were based on subjects of debate in the Netherlands. The questionnaires for the relatives contained only ten of these statements, because in a pilot study five were found to be either too complicated or too much of a burden for them.

Analysis

It was possible that one nurse completed two or more questionnaires, since a nurse could be involved in the decision-making concerning several patients who were included in the study. This occurred in 22 cases, and in these cases we only included data from the first questionnaire completed by the nurse, because the statements were general and did not concern a specific patient. As a result, 148 of the 178 completed questionnaires were included in the analysis.

The responses to these statements were set out against background characteristics such as age, gender, (influence of) religious beliefs (see Table 1). We used a Chi-square test to investigate whether relationships between background characteristics and agreement with the statements were significant. All differences mentioned in the Results section are significant according to this test, unless mentioned otherwise.

Because the nurses and relatives completed the questionnaire on the day on which a decision was made with regard to starting or forgoing ANH, it is possible that their responses were influenced by the status of the patient. We hypothesised that the attitudes of the relatives would be influenced by the patient's status, and that the attitudes of the nurses would not. We used the influence of the patient-related data on the attitudes of the relatives as an outcome measure. The patient-related data were all obtained from the questionnaires completed by the relatives, with the exception of the assessment of the severity of the dementia: this was made by the physician, according to the Bedford Alzheimer Nursing Severity Sub-scale (BANS-S) (Volicer *et al.* 1994). We explored the hypothesis that nurses were not influenced in their responses to the statements by the patient-related data, using two different methods. The first method was by comparing, for the 22 nurses who completed the questionnaire twice, the results of the first and the second questionnaire for each statement, using a paired-samples t-test. The second method was by relating the patient-related data, which were also filled in by the nurses, to the responses to the statements in the first questionnaire completed by 148 nurses.

RESULTS

Background characteristics

The left hand side of Table 1 presents the background characteristics of the physicians, nurses and relatives. The nurses are the youngest group of respondents, with an average age of 34 years. The physicians were somewhat older (average 41 years) and the relatives were the oldest (average 57 years). The right hand side of Table 1 presents patient-related data. Less than 10% of the patients had an advance directive, according to the relatives, and ANH was started in less than 10% of the patients. Most of the relatives (64%) were sons or daughters of the patients.

Table 1 Characteristics of physicians, nurses and relatives who completed the questionnaire and of the patients who were included in the study

	Physicians *n*=107 %	Nurses *n*=148 %	Relatives *n*=136 %		Relatives *n*=136 %
Characteristics of the respondents				**Patient-related data**	
Gender (male)	51	17	38	Advance directive (yes)	7
Age				Decision ANH (starting ANH)	7
• 20—35 years	28	55	1	BANS-S according to physician	
• 36—55 years	71	44	49	(higher is more severe)	
• 56—75 years	1	1	41	• 8—19	46
• 76—92 years	—	—	9	• 20—27	54
Religious beliefs				Pain at the time of ANH	
• No religious beliefs	55	42	38	decision-making	
• Religious beliefs that do not influence ANH decision-making	17	36	42	• None • Very little-moderate • Much-very much	36 53 11
• Religious beliefs that do influence ANH decision-making	28	21	20	Comfort/well-being	
				• Much-moderate	33
				• Little	29
Experience in nursing home care				• Very little	39
• 1 month—4 years	24	26	—	Relationship with the patient	
• 4.5—12 years	44	38	—	• Partner	8
• 12.5—28 years	31	36	—	• Son or daughter	64
Number of patients responsible				• Other	27
for on a daily basis				Religious beliefs of the patient	
• 8—58	47	—	—	• No religious beliefs	28
• 60—150	53	—	—	• Religious beliefs that did not influence ANH decision-making	61
Number of psycho-geriatric patients responsible for on a daily basis					
• 0—34	51	—	—	• Religious beliefs that did	11
• 35—120	49	—	—	influence ANH decision-making	

Patient-related data

It seems nurses were not influenced by patient-related data in their responses to the statements: 22 nurses completed the questionnaire twice and there were no significant differences between their responses to the statements the first and the second time they completed the questionnaire. Furthermore, the first questionnaire completed by 148 nurses showed only one relationship between a statement and a patient characteristic: the nurses disagreed more often with the statement "*It is almost always best not to prevent the death of patients in the advanced stages of dementia*" if the patient in question was assessed with a score below 20 on the BANS-S, implying less severe dementia (34% vs.17%).

Artificial nutrition and hydration

Table 2 shows that, in general, most of the physicians, nurses and relatives agreed (60—65%) with the statement "*When a patient in the advanced stages of dementia refuses to eat*

and/or drink, this should be respected at all times." However, more nurses and relatives than physicians (35% and 47%, respectively, vs. 15%) *fully* agreed that refusal of food and/or drink should be respected. The nurses agreed more often with this statement if they had more experience in nursing home care, as did nurses who stated that their religious beliefs did not influence ANH decision-making.

Table 2 Attitudes towards (artificial) nutrition and hydration concerning nursing home patients with dementia

	Physicians *n*=107		Nurses *n*=148		Relatives *n*=136	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
When a patient in the advanced stages of dementia refuses to eat and/or drink, this should be respected at all times.						
Fully agree	15	(8–22)	35	(28–43)	47	(39–56)
Agree more than disagree	45	(35–54)	27	(20–34)	18	(11–24)
Neither agree nor disagree	16	(9–23)	19	(13–25)	15	(8–21)
Disagree more than agree	21	(13–28)	12	(7–18)	11	(5–16)
Fully disagree	4	(1–9)	6	(3–11)	10	(5–16)
			1 mv		5 mv	
I consider the decision to withhold artificial nutrition and/or hydration from a patient to be negligent medical practice.						
Fully agree	2	(0–7)	2	(0–6)	NA	
Agree more than disagree	2	(0–7)	2	(0–6)		
Neither agree nor disagree	1	(0–5)	3	(1–8)		
Disagree more than agree	15	(8–22)	7	(4–13)		
Fully disagree	80	(73–88)	85	(79–91)		
If a decision is made to forgo artificial nutrition and/or hydration, it is permissible to increase pain medication with the possibility of hastening death.						
Fully agree	28	(20–37)	39	(31–47)	NA	
Agree more than disagree	32	(23–41)	26	(19–33)		
Neither agree nor disagree	12	(6–19)	18	(12–24)		
Disagree more than agree	15	(8–22)	8	(4–13)		
Fully disagree	12	(6–19)	10	(5–15)		
	1 mv		3 mv			
Forgoing artificial nutrition and/or hydration in patients with dementia is almost always followed by a peaceful death.						
Fully agree	45	(35–54)	28	(21–36)	27	(19–35)
Agree more than disagree	44	(35–53)	29	(22–36)	22	(15–30)
Neither agree nor disagree	7	(3–14)	24	(17–31)	42	(33–51)
Disagree more than agree	3	(1–8)	11	(6–17)	5	(2–11)
Fully disagree	1	(0–5)	7	(3–12)	3	(1–8)
					15 mv	

MV=missing value
NA=not asked
CI=confidence interval

The relatives agreed more often if they thought that their demented relative had more pain and a lower degree of comfort at the time when the decision about ANH was made.

Few physicians or nurses (4% in each group) agreed with the statement "*I consider the decision to withhold artificial nutrition and/or hydration from a patient to be negligent medical practice.*" Most of the physicians and nurses (60% and 65%, respectively) agreed with the statement "*If a decision is made to forgo artificial nutrition and/or hydration, it is permissible to increase pain medication with the possibility of hastening death.*"

Physicians agreed more often than nurses and relatives (89% vs. 57% and 49% respectively) with the statement "*Forgoing artificial nutrition and/or hydration in patients with dementia is almost always followed by a peaceful death.*" The nurses agreed more often with this statement if they had more experience in nursing home care, varying from 37% of the least experienced nurses (*n*=30, up to three years of experience) to 70% of the most experienced nurses (*n*=27, 20 years or more of experience)

Table 3 Attitudes towards advance directives

	Physicians *n*=107		Nurses *n*=148		Relatives *n*=136	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
On admission, the treating physician should routinely ask the patient or the patient's family about any possible wishes concerning the end of the patient's life.						
Fully agree	44	(35–53)	61	(53–69)	78	(71–85)
Agree more than disagree	35	(26–44)	18	(12–24)	10	(5–16)
Neither agree nor disagree	7	(3–14)	10	(5–15)	5	(2–11)
Disagree more than agree	13	(7–20)	4	(2–9)	2	(0–6)
Fully disagree	1	(0–5)	7	(3–12)	5	(2–11)
			1 mv		2 mv	
An advance directive should always be followed.						
Fully agree	5	(2–11)	51	(43–59)	73	(66–81)
Agree more than disagree	32	(23–41)	27	(20–34)	15	(9–21)
Neither agree nor disagree	21	(14–29)	14	(9–20)	8	(4–14)
Disagree more than agree	25	(17–34)	2	(0–6)	1	(0–4)
Fully disagree	17	(10–24)	5	(2–10)	3	(1–8)
					5 mv	
An advance directive of a patient who has become incompetent is no longer valid.						
Fully agree	1	(0–5)	9	(5–15)	NA	
Agree more than disagree	6	(2–12)	5	(2–10)		
Neither agree nor disagree	9	(5–17)	16	(10–21)		
Disagree more than agree	44	(35–53)	22	(16–29)		
Fully disagree	40	(31–50)	47	(39–55)		

MV=missing value
NA=not asked
CI=confidence interval

Advance directives

Table 3 shows that, in general, the physicians, nurses and relatives agreed (79%—88%) with the statement "*On admission, the treating physician should routinely ask the patient or the patient's family about any possible wishes concerning the end of the patient's life.*" However, more relatives than nurses, and more nurses than physicians (78%, 61% and 44% respectively) *fully* agreed with this statement. With regard to the statement "*An advance directive should always be followed.*", 78% of the nurses and 88% of the relatives agreed, but only 37% of the physicians agreed. Non-religious nurses agreed with this statement more often than nurses who had religious beliefs which they considered to be of influence in their decision-making (96% vs. 72%). Of the 10 relatives of the patients who actually had an advance directive, 9 agreed with this statement and one did not give an opinion.

Few physicians or nurses (7% and 14%, respectively) agreed with the statement "*An advance directive of a patient who has become incompetent is no longer valid.*" Again the religious beliefs of the nurses were related to their attitude: 5% of the nurses who were not religious agreed, 17% of the nurses who had religious beliefs but considered them to be of no influence agreed, and 32% of the nurses who did consider their religious beliefs to be of influence agreed.

Hastening death

Table 4 shows that the relatives agreed more often than the physicians and nurses (64% vs. 23% and 27%, respectively) with the statement "*Patients in the advanced stages of dementia are totally unable to indicate when they no longer want to live.*" However, relatives who stated that their religious beliefs or the religious beliefs of their demented relative had an influence on their decision-making agreed much less often (41% and 21%, respectively).

The nurses agreed less often than the physicians and relatives (55% vs. 72% and 79% respectively) with the statement "*It is almost always best not to prevent the death of patients in the advanced stages of dementia.*" Relatives fully agreed with this statement most often (63% vs. 29% of physicians and 35% of nurses). The partners and children of demented patients agreed less often with this statement than people who were related to the patient in other ways (73% vs. 94%).

Of the physicians and nurses, 27% and 55%, respectively, agreed with the statement "*I think physician-assisted death without a request is permissible in an incompetent patient if you know that recovery is impossible and the remainder of the patient's life will be agony.*" Both groups showed a trend that religious beliefs led to less agreement, but this trend was only significant for nurses: agreement was 64% among nurses who were not religious, 54% among nurses who thought that their religion had no influence on the decision-making, and 39% among nurses who did think that their religious beliefs had an influence on the decision-making.

Table 4 Attitudes towards hastening the death of patients in the advanced stages of dementia

	Physicians *n*=107		Nurses *n*=148		Relatives *n*=136	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
Patients in the advanced stages of dementia are totally unable to indicate when they no longer want to live.						
Fully agree	6	(2—12)	16	(10—21)	53	(44—61)
Agree more than disagree	17	(10—24)	11	(6—16)	11	(6—16)
Neither agree nor disagree	9	(5—17)	12	(7—17)	10	(5—16)
Disagree more than agree	50	(40—59)	33	(26—41)	19	(13—26)
Fully disagree	19	(11—26)	28	(21—36)	7	(4—13)
					1 mv	
It is almost always best not to prevent the death of patients in the advanced stages of dementia.						
Fully agree	29	(20—38)	35	(27—43)	63	(54—71)
Agree more than disagree	43	(34—52)	20	(13—26)	16	(10—22)
Neither agree nor disagree	18	(11—25)	22	(15—28)	15	(8—21)
Disagree more than agree	7	(3—13)	10	(5—15)	4	(1—9)
Fully disagree	4	(1—9)	14	(8—19)	3	(1—8)
					5 mv	
I think physician-assisted death without a request is permissible in an incompetent patient if you know that recovery is impossible and the remainder of the patient's life will be agony.						
Fully agree	5	(2—11)	28	(21—35)	NA	
Agree more than disagree	22	(15—30)	27	(20—34)		
Neither agree nor disagree	15	(8—22)	18	(12—25)		
Disagree more than agree	23	(15—31)	8	(4—14)		
Fully disagree	35	(26—44)	18	(12—25)		
			2 mv			

MV=missing value
NA=not asked
CI=confidence interval

Self-determination and euthanasia

Table 5 shows that the majority of the physicians, nurses and relatives agreed (78—84%) with the statement "*Everyone has the right to decide about his/her own life and death.*", and that the majority of the nurses and the relatives (63% and 62%, respectively) fully agreed with this statement. Physicians less often fully agreed with this statement (34%). In all groups there was a trend towards people who were more religious agreeing less often with this statement, but among the physicians the trend was not significant.

Relatives agreed more often than nurses, and nurses agreed more often than physicians (90%, 57% and 16%, respectively) with the statement "*Euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent.*" As with the previous statement, all three groups showed a trend towards people who were more religious agreeing less often with this statement. None of the physicians who had completed the specific training for nursing home physicians (*n*=39) agreed with this statement. The relatives of the 10 patients who actually had an advance directive all agreed with this statement, and the relatives of the 3 patients with an advance *euthanasia* directive fully agreed with this statement.

The statement "*If a demented patient signed an advance euthanasia directive when he or she was still competent, it is*

impossible to decide when this request should be granted." was agreed with by 78% of the physicians and 40% of the nurses.

Policy concerning forgoing treatment

Table 6 shows that most of the physicians, nurses and relatives agreed (87%—95%) with the statement "*In decisions to forgo treatment the well-being of the patient always outweighs the well-being of the patient's relatives.*" The relatives more often fully agreed with this statement than the physicians and nurses (87% vs. 50% and 64%).

Most of the physicians, nurses and relatives agreed (72%—75%) with the statement "*There should be guidelines for decisions concerning forgoing possible life-prolonging treatment.*" The physicians fully agreed with this statement less often than the nurses and relatives (28% vs. 51% and 62%).

Table 5 Attitudes towards self-determination and euthanasia based on an advance euthanasia directive

	Physicians *n*=107		Nurses *n*=148		Relatives *n*=136	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
Everyone has the right to decide about his/her own life and death.						
Fully agree	34	(25—43)	63	(55—71)	62	(53—70)
Agree more than disagree	46	(36—55)	15	(9—21)	22	(15—30)
Neither agree nor disagree	8	(4—15)	12	(7—18)	8	(4—14)
Disagree more than agree	11	(5—17)	5	(2—10)	6	(3—12)
Fully disagree	1	(0—5)	5	(2—10)	2	(0—7)
			2 mv		6 mv	
Euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent.						
Fully agree	1	(0—5)	30	(23—38)	74	(67—82)
Agree more than disagree	15	(8—22)	27	(20—34)	15	(9—22)
Neither agree nor disagree	15	(8—22)	23	(16—30)	6	(3—12)
Disagree more than agree	32	(23—41)	10	(5—15)	2	(0—7)
Fully disagree	37	(28—47)	10	(5—15)	2	(0—6)
			2 mv		11 mv	
If a demented patient signed an advance euthanasia directive when he or she was still competent, it is impossible to decide when this request should be granted.						
Fully agree	43	(34—52)	24	(17—31)	NA	
Agree more than disagree	35	(26—44)	16	(10—22)		
Neither agree nor disagree	7	(3—13)	31	(23—38)		
Disagree more than agree	14	(7—21)	19	(13—26)		
Fully disagree	2	(0—7)	10	(5—15)		
			2 mv			

MV=missing value
NA=not asked
CI=confidence interval

Table 6 Attitudes towards policy concerning forgoing treatment

	Physicians *n*=107		Nurses *n*=148		Relatives *n*=136	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
In decisions to forgo treatment the well-being of the patient always outweighs the well-being of the patient's relatives.						
Fully agree	50	(40–59)	64	(57–72)	87	(81–93)
Agree more than disagree	43	(34–52)	23	(16–30)	8	(4–14)
Neither agree nor disagree	4	(1–9)	9	(5–15)	4	(1–9)
Disagree more than agree	4	(1–9)	2	(0–6)	1	(0–4)
Fully disagree	0	(0–3)	1	(0–5)	0	(0–3)
			2 mv		4 mv	
There should be guidelines for decisions concerning forgoing possible life-prolonging treatment.						
Fully agree	28	(20–37)	51	(43–60)	62	(54–71)
Agree more than disagree	44	(35–54)	21	(14–27)	13	(7–18)
Neither agree nor disagree	14	(8–21)	10	(5–15)	11	(6–17)
Disagree more than agree	11	(5–17)	10	(5–15)	7	(3–13)
Fully disagree	2	(0–7)	8	(4–13)	7	(3–13)
	1 mv		2 mv		9 mv	

MV=missing value
CI=confidence interval

DISCUSSION AND CONCLUSION

Limitations

A limitation of this study is that we cannot exclude the possibility that differences between physicians, on the one hand, and relatives and nurses on the other hand, were a result of the fact that the data were collected in different phases of the decision-making process. However, we found no indications of an important influence of the status of the patient on the attitudes of the nurses. We therefore consider it plausible that the physicians would not have reported different attitudes at any other point in time. Another limitation of this study is that self-reported attitudes can differ from actual behaviour.

Religious beliefs

Respondents who stated that their religious beliefs did influence their ANH decision-making often had a more conservative attitude towards several end-of-life decisions. It might be considered more acceptable if physicians and nurses only allow their religious beliefs to influence decision-making if these beliefs are shared by the patient and the relatives, but it could be unethical if this happened if such beliefs were not shared. It is therefore important for physicians and nurses to be aware of differences in religious beliefs and to learn how to incorporate this into communication about end-of-life decisions.

Artificial nutrition and hydration

Most physicians and nurses think that a decision to forgo ANH can be good medical practice. This is in agreement with the standpoints of the official medical associations in the Netherlands (Dutch Association of Nursing Home Physicians, 1997; Royal Dutch Medical Association, 1997). This also concurs with actual practice in the Netherlands: ANH is forgone in 94% of nursing home patients with dementia for whom a decision concerning ANH was made (Pasman *et al.* 2004). A smaller majority also agrees that it is permissible to subsequently increase pain medication with the possibility of hastening death. Whereas the majority of

physicians, nurses and relatives think that refusal of food and drinks by a patient should be respected, a large majority of physicians only, think that a decision to forgo ANH is almost always followed by a peaceful death. Relatives often have no opinion about the peacefulness of a death after a decision to forgo ANH, probably because they simply do not have the experience to judge this. Nurses agree less often than physicians that forgoing ANH is almost always followed by a peaceful death, possibly because, compared with physicians, they see more of the process of dying. Another explanation could be that nurses might have higher standards concerning "a peaceful death". The difficulty is that it is not possible to determine whose opinion is closest to reality, because it is not possible to measure the experiences of patients in the advanced stages of dementia objectively. However, systematic observations suggested that decisions to forgo ANH in these patients were not associated with high levels of discomfort (Pasman *et al.* 2005). It could be valuable to inform relatives and nurses of these results and to discuss opinions about this issue openly.

Advance directives

Physicians, nurses and relatives all agree on the importance and validity of advance directives. This is in itself interesting as the validity of advance directives, especially in case of dementia, has been much debated. However, a discrepancy between physicians and relatives, in particular, becomes apparent in their response to the statement "*An advance directive should always be followed*." Whereas the patients and their relatives probably think that advance directives have to be followed by physicians, the physicians know that only certain types of advance directives are binding. The majority of older people in the Netherlands with an advance directive, have an advance *euthanasia* directive, that is not only non-binding, but —at the time of this study— the euthanasia legislation did not explicitly mention the legal status of advance euthanasia directives, which implies that following an advance euthanasia directive might have led to prosecution of the physician (Rurup *et al.* 2005; Klinkenberg *et al.* 2004). This discrepancy in attitudes could therefore be caused by the different roles of the people involved: people who can express their wishes in the form of advance directives want them to be followed, physicians who have to execute the wishes of these people are responsible, and will usually only consider following an advance directive if this is consistent with the law. This difference in responsibility could also explain why physicians fully agree less often than nurses and relatives that everyone has the right to decide about their own life and death.

Communication with the patient

There is a noticeable difference in opinion between physicians and nurses versus relatives with regard to their beliefs about whether patients in the advanced stages of dementia are still able to indicate when they no longer want to live. It is possible that relatives lack the expertise to know how to communicate with severely demented patients. However, this seems unlikely because the relatives know the patient very well and therefore should be able to communicate best with their own relative. It is also possible that physicians and nurses are used to trying to communicate with patients in the advanced stages of dementia, and are therefore more easily satisfied than the relatives with indications of how a patient is doing, because the relatives still have their previously non-demented relative in mind. This difference in perspective with regard to the patient, together with the difference in responsibility, could also explain why the majority of the relatives are of the opinion that euthanasia is permissible for incompetent patients if they have signed an advance euthanasia directive, and the majority of the physicians think that this is not permissible. The relatives probably attach more importance to what they consider to be the interests of the patient from the perspective of the entire life of the patient, and the physicians attach more importance to what they consider to be the interests of the patient with dementia at the present time.

Conclusion

In general, physicians, nurses and relatives agree on many aspects of end-of-life decision-making for nursing home

patients with dementia. However, on some issues the outcomes of the decision-making may differ. Although physicians, nurses and relatives are all guided by the best interest of the patient, differences in religious beliefs, differences in perspective of the patient (entire life of the person vs. the patient with dementia at the present time), and differences in responsibility can lead to different outcomes.

Practice implications

Physicians should discuss end-of-life decisions more openly. Most relatives, physicians and nurses thought that on admission, the treating physician should routinely ask the patient or the patient's family about any possible wishes concerning the end of the patient's life, but this occurs in only 68% of the cases in the Netherlands (Pasman *et al.* 2004). If physicians have reason to believe that forgoing ANH in patients with dementia is almost always followed by a peaceful death, they should discuss this with nurses and relatives. Furthermore, physicians, who greatly influence decisions concerning the end of life of nursing home patients in the Netherlands, should be aware of the influences on attitudes concerning end-of-life decision-making, such as differences in religious beliefs, differences in perspective of the patient (entire life of the person vs. the patient with dementia at the present time), and differences in responsibility, and should be able to incorporate them into communication about end-of-life decisions. This could improve the quality of end-of-life decision-making.

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Part 4
General Discussion

The research questions I posed at the beginning of this thesis were the following:

- How many people request euthanasia or assisted suicide (EAS) because they are 'weary of life', what are the characteristics of these people, and how often do physicians grant such requests?
- What do physicians and the general public think about EAS in the absence of a severe disease, and a 'suicide pill' for older people?
- How many patients have an advance directive concerning euthanasia, and what are physicians' experiences with demented patients who have an advance euthanasia directive?
- What are the attitudes of physicians, nurses and relatives of patients suffering from dementia concerning advance euthanasia directives and other end-of-life decisions?

I will first discuss some methodological considerations and limitations of the studies described in this thesis. Then I will discuss the answers to the research questions, recent developments and several current subjects of debate —including expectations for the future— concerning euthanasia for people who are weary of life and successively concerning euthanasia in cases of advanced dementia. Finally, some recommendations will be made for future policies and research.

8.1 METHODOLOGICAL CONSIDERATIONS

Retrospective self-report

The results presented in Chapters 2, 3 and 6, concerning requests for EAS in the absence of a severe disease, requests from patients who are tired of living, and requests in cases of advanced dementia by means of an advance euthanasia directive, depend on reports by the physicians, and not on observations of actual practice. This is an important limitation, because it can bias the results in several ways. It is possible that physicians who were asked to describe their most recent case, in fact accidentally reported their most memorable case. This could lead to misrepresentation if the memorable cases differ in relevant aspects from the most recent cases. It is also possible, if the physicians felt that the most recent case would reflect badly on them, that they intentionally presented another case, and not the most recent one, or that they denied having had such a case at all. They might even have feared prosecution, even though anonymity was guaranteed, and the interviewers were specifically trained to prevent such bias. This, again, could lead to misrepresentation, or to an under-estimation of the incidence. Bias could also occur in the case itself: a physician who had granted a request for EAS might emphasise the burden of the symptoms, and tone down the aspects, such as depressive symptoms, that would make granting the request questionable. On the other hand, it is possible that refusing a request is justified by the same process, but vice versa. The results presented in Chapters 2, 3 and 6 therefore depend on the reliability and honesty of the reports by the physicians.

Perspective of the physician

The chapters describing the practice of requests for EAS, describe it from the perspective of the physician, and not from the perspective of the patient. A physician might tend to emphasise the medical aspects of suffering, and pay less attention to social problems. As a result, social problems, that play an important role for patients who are tired of living as well as for patients with dementia, may be under-estimated and under-exposed in this thesis. Further research is required to investigate the perspective of the patient.

Attitudes

The attitudes of various people, as presented in Chapters 4 and 7, are of little value if these people have not given much thought to the subject. In Chapter 4 we provided only limited information about the 'suicide pill' to explain the question to be answered, but that did not influence the attitude. It is possible that the findings would have been very different if more information was provided about arguments in favor or against a suicide pill and self-determination at the end of life. In Chapter 7 only those people who were directly involved with patients with advanced dementia were asked about their attitudes,

because we assumed that their attitude would be reasonably stable.

Response

All the studies described in this thesis had a high response rate. Some data on the non-responders were collected in the various studies, and in most of the relevant aspects no difference was found between responders and non-responders.

Developments

All the studies described in this thesis, with the exception of the LASA study, were performed very recently when this thesis was published (between 2000—2002, LASA in 1998). The fact that the LASA study was somewhat older might have led to an under-estimation of the prevalence of advance directives, because some have suggested that the prevalence of advance directives is increasing or will increase in the future, although there appears to be no evidence for such an increase. In spite of the fact that the results seem to be up-to-date at present, it could be said that the findings in this thesis are only reliable as estimates of EAS practice over a short period of time. The new 2002 euthanasia legislation may already have led to changes in the practice of EAS. It is therefore important that similar studies are performed periodically to analyse developments in these practices.

8.2 WEARY OF LIFE

How many people request EAS because they are 'weary of life', what are the characteristics of these people, and how often do physicians grant such requests?

At the start of this study, there was very little available information about requests for EAS in the absence of a severe disease or about how often such requests were made. The only concrete information was the report about the Brongersma case. In this thesis it has been explained that the request of Brongersma was not an incident, but that it represents the standpoint of a large group of older people who wish to die and therefore request EAS. We estimate that each year 400 people in the Netherlands request EAS, not because they have a severe disease, but because they are 'weary of life'. Although people who request EAS in the absence of a severe disease appear to be a heterogeneous group that cannot be described uniformly, it can be said that many people in this group suffer from the physical decline that is associated with ageing, in combination with the feeling that they have no valuable role left in life. In all likelihood, this group of older people is part of a much larger group of older people who have a wish to die, but *do not* request EAS. Studies in Sweden, Italy, the UK and Germany have shown that approximately 10—15% of older people had death or suicidal ideation in the past year (Skoog *et al*. 1996; Scocco and De Leo, 2002; Rao *et al*. 1997; Barnow and Linden, 2000). If these results also apply to the Netherlands, this would mean that about 200,000—300,000 older people in our country have death or suicidal ideation.

Depression

In the Netherlands it is generally accepted that people who are not suffering from a clinical depression can request EAS. However, especially in other countries, not everybody agrees with this attitude (Linden and Barnow, 1997). According to the physicians in our study, there are patients who request EAS because they are weary of life who do not suffer from a clinical depression or any other severe psychiatric or physical disease. As we did not include extensive screening for depression in our studies, we cannot rule out the possibility that some of these patients suffered from a clinical depression that was undiagnosed by their physician.

As a death wish, in itself, is a symptom of clinical depression, according to the DSM-IV (American Psychiatric Association, 1994), it seems likely that people who request EAS more often suffer from depression than people who do not request EAS. In severely ill patients there is some proof of a positive association between depression and considering or requesting EAS (Emanuel *et al*. 2000). However, these results should be interpreted with caution, because it is difficult to assess the extent to which depressive symptoms are 'normal' in terminally ill patients, or when they indicate depression (Block, 2000).

Furthermore, studies on death and suicidal ideation in samples of older people (not discriminating between people who were ill and those who were not) have reported positive associations between a death wish and several types of mental illnesses, among which depression (Skoog *et al.* 1996; Scocco and De Leo, 2002; Rao *et al.* 1997; Barnow and Linden, 2000; Linden and Barnow, 1997).

In the international context, the assumption that patients who request EAS suffer from a clinical depression is often made with the intention to preclude EAS requests as a result of a psychiatric condition (Barnow and Linden, 2000). However, in the Dutch context, depression could provide the medical cause that became a legal requirement after the verdict in the Brongersma case. Nevertheless, research has shown that, in practice, physicians are much less willing to perform EAS for patients with a psychiatric disease than for patients with a physical disease (van der Wal *et al.* 2003; van der Wal and van der Maas, 1996). Moreover, physicians are more likely to refuse a request for EAS from a patient with a severe physical disease if a patient also suffers from depressive symptoms or a clinical depression (Rurup *et al.* 2005; Jansen-van der Weide *et al.* 2005). This is understandable, because if someone suffers from depression it is possible that their request for EAS is not well-considered, because their competence may be compromised, and treatment for the depression may still be possible. Someone who requests EAS in the absence of a disease does not necessarily suffer from a clinical depression, but extra attentiveness to depressive symptoms is justified in such cases. In future studies investigating possible treatment to eliminate death wishes or make them less intense this may be an interesting angle, because even if a patient does not meet the DSM-IV criteria for depression, some types of treatment that are normally given for depression may have the effect of lessening depressive symptoms, such as a wish to die (De Lima and Hotopf, 2003).

Medical domain

The results presented in Chapter 2 of this thesis show that one-third of the general practitioners and nursing home physicians had received a request for EAS in the absence of a severe disease, and that most of these requests had been refused. If the physician proposed an alternative treatment, this was frequently refused by the patient, and most patients persisted in their request for EAS. Nevertheless, some patients who received treatment withdrew their request. This could be a reason to assume, apart from the question of whether a physician should ever grant a request in the absence of a severe disease, that it is a physician's task to know how to treat people who are weary of life. However, the verdict of the Dutch Supreme Court in the Brongersma case places such requests outside the medical domain (Dutch Supreme Court, 2002). The Supreme Court ruled that the presence of a medical cause justifies the physician to form a professional opinion about the suffering of the patient, the prognosis and the alternatives, but that physicians do not have the specific expertise to assess weariness of life.

The results presented in Chapter 3 of this thesis cast doubt on whether it is possible to define the borders of the medical domain so clearly. Chapter 3 shows that the burden of symptoms is high for people who request EAS in the absence of a severe disease. Each of the three symptoms that were reported most frequently in patients with cancer or other severe diseases —feeling bad, tired and inactive— were also reported by over half of the patients who did not suffer from a severe disease. This implies that non-severe diseases and old age can cause symptoms that are similar to those caused by severe diseases. Furthermore, being tired of living also occurs in the presence of a severe disease, in absolute numbers even more often than in the absence of severe disease. According to the physicians, being tired of living was an important reason for the patient to request EAS in as much as 17% of the cases. In such cases, the physician is apparently considered to be competent to deal with a patient who is tired of living. Excluding tiredness of living from the expertise of the physician seems to ignore the fact that people with a severe disease do not usually request EAS exclusively for medical reasons, but also because of the complex psychological effects of their medical condition and its consequences. Previous research has shown that in most cases the main reasons underlying an EAS request are not physical symptoms, such as pain, but psychological reasons, such as loss of dignity, deterioration and loss of meaning in life (van der Wal *et al.* 2003; Meier *et al.* 2003). In addition to showing that the

medical domain is not so easily defined, Chapter 3 also shows that the requirements of due care appear to be sufficient guidance for physicians to assess requests for EAS from people who are tired of living. A multivariate analysis showed that compliance with the requirements of due care was more important in the physician's assessment than the presence or absence of a severe disease. In the requests that were granted, the requirements of due care were not always met, but similar due care was provided in all cases of EAS (Haverkate *et al.* 2000).

The Royal Dutch Medical Association (RDMA) established a committee to analyze the legitimation and limits of EAS, and their implications for EAS in the absence of a severe disease (Dijkhuis and Committee Members, 2004). In a report published in December 2004, this committee concluded that requests for EAS in the absence of a severe disease can be granted, although they should be assessed strictly according to the regulations. This conclusion is, obviously, in contrast to the verdict of the Supreme Court. The committee based this conclusion on five arguments (see Box 1). The second argument, i.e. that the legal demarcation of a medical cause is not in line with the complexity of practice, is very similar to the conclusions drawn in Chapter 3, as summarized above. The fourth argument states that even if treating people who are weary of life is not a basic task, this does not mean that physicians cannot acquire the expertise to deal with requests for EAS in the absence of a severe disease. This is supported by the results of Chapter 2, which showed that some physicians were able to treat patients in such a way that they withdrew their request for EAS. The fifth argument is that people will consider a physician the right person to turn to with a request for EAS. This is especially interesting, since it does not exclusively concern the aspect of legitimation, but is rather a question of 'supply and demand'. This argument could have led simply to the conclusion that physicians should extend their expertise to deal with the problems of people who are 'suffering from life', but the committee apparently thinks that requests should also be taken seriously, if only because people have no one else to turn to with a request for EAS. A suicide pill is not considered to be a realistic alternative, because medical expertise is required for the actual performance of EAS, and also for the determination of competence and alternatives in cases of depression. The committee is of the opinion that another type of assessment might be an option for patients who do not have a severe disease, in which physicians have a less important role, although it is doubtful whether it would be possible to combine two disparate models in one jurisdiction.

Box 1

The Royal Dutch Medical Association committee concluded that a medical cause should not be a requirement for EAS, because:

1) the cause of the suffering does not determine the extent to which the suffering is experienced, and unbearable and hopeless suffering can occur in the absence of severe disease,
2) the legal demarcation of a medical cause is not in line with the complexity of practice,
3) physicians do have expertise in the area of 'suffering from life', and this expertise can be extended,
4) although opinions differ on whether or not dealing with 'suffering from life' is part of the task of the physician, consensus is not required, since physicians should be able to set their own limits, provided that they acquire the necessary expertise, and
5) requests will occur more frequently in the future because people will be more outspoken, they will become more familiar with the concepts of autonomy, as life expectancy increases they will experience more physiological symptoms and limitations of old age, and they will consider the physician the right person to turn to with a request for EAS.

8.3 SUICIDE PILL

What do physicians and the general public think about EAS in the absence of a severe disease, and a 'suicide pill' for older people?

The general population was more in favor of enabling older people to obtain medication to end their life if they so wish than the physicians were (45% vs. 25%). Nevertheless, only 15% of the general population thought that a suicide pill should be made available. It seems unlikely, with such little public support, that any politician will be willing to burn his fingers by actively supporting a suicide pill. The relatives of patients who died after EAS were more in favor of a suicide pill than the general population (36%), and the reason they gave was that people should have the right to decide about their own life and death. The most important argument against the suicide pill was "fear of taking such a pill when depressed or on impulse" (42%). Although 74% of the physicians considered it inconceivable that they would ever grant a request for EAS in the absence of a severe disease, 30% of the relatives were against a suicide pill because they preferred the involvement of a physician. The general population also appears to prefer the involvement of a physician, as can be derived from the fact that 45% thought that very old people should be able to obtain medication with which they can end their life if they so wish, but only 15% were in favor of a suicide pill.

Are arguments against a suicide pill somehow less relevant if a physician is involved? The arguments given by the respondents in Chapter 4 and the arguments mentioned originally by Drion, and later in debates about a suicide pill and EAS, are summarized in Table 1 (Drion, 1991; Rurup *et al.* 2005; van Trappenburg and Holsteyn, 2001; Beauchamp and Childress, 1994). They are classified as: in favor or against, and as practical or normative arguments, and a comparison is made of which arguments apply to a suicide pill (without the involvement of a physician) and which apply to EAS in the absence of a severe disease (with the involvement of a physician)[a]. Chapter 4 showed that most people who were in favor of a suicide pill gave as reason that they wanted to decide about their own life, which is interpreted as the 'right to autonomy' in Table 1. Most people who were against a suicide pill, gave practical arguments, such as a fear of taking such a pill when depressed, or on impulse.

When we compare the arguments that apply to a suicide pill *without* the involvement of a physician with those that apply *with* the involvement of a physician, we can see that a physician can exercise control in such a way that most practical counter arguments become invalid. A physician can ensure that suicide pills are not taken impulsively or when people are depressed, by assessing the request and offering alternatives. The prescription of such a pill by a physician can also prevent misuse and accidents. Therefore, a physician would not only control distribution, but could also be a medium for societal control. Physicians can be steered in certain directions by regulations with regard to when they can and cannot supply people with lethal medication, which is also a reassurance that there will not be an excess of suicides. The involvement of a physician makes many counter arguments invalid, but it also takes away the certainty that people can end their life if they so wish, as was intended with a suicide pill in the original argument put forward by Mr. Drion (Drion, 1991). His hypothesis was that not many people will take the suicide pill before they become very ill as long as they are sure that they can end their life whenever they so wish. A further practical counter argument related to the involvement of a physician is that EAS in the absence of a severe disease should perhaps not be a physician's task. This raises the question of whether or not someone else could be considered competent to distribute the suicide pill.

[a] A strict distinction between practical and normative arguments is not possible, because some arguments are inter-related (the importance of not taking pills on impulse must be derived from another argument, e.g. the sanctity of life).

Table 1 Arguments in favor and against a suicide pill (without the involvement of a physician) and EAS (with the involvement of a physician) in the absence of severe disease

	In favor			Against		
Practical arguments	Ending life in a more dignified way	*Applies with a suicide pill*	*Applies with EAS*	Bereavement of the relatives	*Applies with a suicide pill*	*Applies with EAS*
	Reassurance for older people that they can end their life if they so wish	*Applies with a suicide pill*	—	Pills might be taken when depressed or on impulse, there might have been alternatives	*Applies with a suicide pill*	—
	Opportunity to assess the wish to die and offer alternatives	—	*Applies with EAS*	Possibility of misuse for murder	*Applies with a suicide pill*	—
	The responsibility is shared between physician and patient, and the physician can subsequently be held accountable	—	*Applies with EAS*	Accidents with lethal medication	*Applies with a suicide pill*	—
				Suicide becoming an accepted practice with a low threshold could threaten social stability	*Applies with a suicide pill*	—
				Should not be a physician's task	—	*Applies with EAS*
Normative arguments	Right to autonomy	*Applies with a suicide pill*	*Applies with EAS*	Sanctity of life or intrinsic value of life dictates that an attempt should be made to save every life	*Applies with a suicide pill*	*Applies with EAS*
	Justice: some people can already obtain lethal medication	*Applies with a suicide pill*	*Applies with EAS*	Negative valuation of the life of older people	*Applies with a suicide pill*	*Applies with EAS*

Table 1 also makes it clear that the debate about the system of distributing lethal medication to older people with a wish to die only affects the practical arguments, while the normative arguments remain the same. Strong practical arguments can sometimes influence normative arguments. For instance, if an experiment with a suicide pill as once suggested by the Dutch Association for Voluntary Life-termination (NVVE) had been carried out and had shown that the number of suicides would have decreased as a result of the reassurance that people can end their life if they so wish, this would have weakened the argument against a suicide pill that an attempt should be made to save every life because of its intrinsic value. However, practical arguments cannot usually overcome normative

arguments. People who are convinced that suicide is wrong will not be persuaded that a suicide pill should be made available just because a very good system of distribution has been established. It is noticeable that hardly any normative counter arguments were mentioned by the respondents. This could be due to selection bias, because the respondents who answered this question were relatives of people who had died after EAS. It is also possible that they simply did not think of a relatively complex argument, i.e. that a suicide pill would imply a negative valuation of the life of older people. In a similar study, in which people did not state their own opinions, but were asked whether or not they agreed with statements, 42% agreed that a suicide pill is not a good idea, because it could make elderly people feel expendable (van Trappenburg and Holsteyn, 2001).

Almost the same arguments apply to EAS in the *presence* of a severe disease and EAS in the *absence* of a severe disease, except for the argument that EAS would imply a negative valuation of the life of older people, which should be replaced by the argument that EAS could imply a negative valuation of the life of severely ill or disabled people. In the classical Dutch debate on EAS for severely ill people, these normative arguments against EAS were not decisive, and the right to autonomy and the possibility to end one's life in a dignified way were considered to be more important. However, it is possible that these arguments are weighed differently in the absence of a severe disease.

Expectations for the future

EAS in the absence of a severe disease is illegal, but it is impossible to predict whether or not it will be legalized in the future. The possibility is currently excluded according to case law: the necessity of a medical cause is clearly stated in the Brongersma case. However, this case law was based on the assumption that negative consequences of aging are normal (i.e. not diseases), thereby prohibiting the physician —a medical expert— to perform EAS for people who are weary of life. This argument is opposed by the Dijkhuis committee, which emphasises the physical suffering of people who are weary of life, and considers that physicians are capable of acquiring the necessary expertise. It is not inconceivable that, as more and more consequences of ageing become treatable, the medical consensus will shift and the negative physical consequences of old age will less often be considered as 'normal'. Such a shift would call for a reassessment of the existing case law concerning weariness of life if a new lawsuit occurred — because case law has always followed the medical consensus in cases of EAS.

It would appear to be more likely at present that EAS in the absence of a severe disease would be legalized than that a suicide pill would be made available, because the public support for a suicide pill is currently very low, and there is no political party that actively advocates a suicide pill. However, things could change in the future. A suicide pill distribution system which overcomes the practical arguments against such a pill is conceivable, especially since the NVVE, a large association with more than 100,000 members, is actively developing and advocating such a system. If they are able to develop a new system that eliminates the practical counter arguments, they will revive the suicide pill debate, and it remains to be seen what the outcome would then be.

8.4 ADVANCE DIRECTIVES

How many patients have an advance directive concerning euthanasia, and what are physicians' experiences with demented patients who have an advance euthanasia directive?

From Chapter 5 it is clear that relatively few people have a living will, i.e. an advance directive in which they specify which treatment, care, etc. they would want to receive (positive advance directives) or would not want to receive (negative advance directives) under certain circumstances. People who did have such a directive usually had an advance *euthanasia* directive. More people had appointed representatives, verbally or in writing, to make decisions for them if they should become unable to make their own decisions. Even though only a small percentage of the population in the Netherlands has a living will, the absolute number of people with a living will is still very high.

Chapter 5 does not provide any insight into the situations in which people want euthanasia. As described in the

Introduction, advance euthanasia directives are intended for situations in which patients have become incompetent to make their own decisions, but are sometimes improperly used as a recording of the wishes of competent patients. Nevertheless, a recent NVVE report does show that they are frequently formulated for use in situations of incompetence. Of the 103,500 NVVE members, approximately 72% have stated in writing that they want euthanasia if they become demented (NVVE, 2004).

In Chapter 6 of this thesis it is reported that each year approximately 2,200 demented patients with an advance euthanasia directive die. In 76% of such cases, it was discussed whether or not to comply with the directive. Although advanced dementia, in itself, is usually not considered to meet the requirement of unbearable suffering, physicians can comply with an advance euthanasia directive if the patient has symptoms indicating serious suffering. However, most physicians thought it inconceivable that they would ever comply with the advance euthanasia directive of a demented patient. Of the 40 nursing home patients with advanced dementia who had an advance euthanasia directive, as described in Chapter 6, in two cases the physician had administered drugs with the explicit intention to hasten the death of the patient. In both cases the patient suffered from an additional illness and had symptoms indicating serious suffering, but it was uncertain whether the life of the patient had, indeed, been shortened, since the physicians had not used the recommended euthanasia drugs.

What are the attitudes of physicians, nurses and relatives of patients suffering from dementia concerning advance euthanasia directives and other end-of-life decisions?

In general, physicians, nurses and relatives agree on many aspects of end-of-life decision-making for nursing home patients with dementia. However, on some issues their attitudes differ. Compared to physicians, relatives attach more importance to advance directives, and have a more permissive attitude towards hastening death. Although physicians, nurses and relatives are all guided by the best interest of the patient, it seems that differences in religious beliefs, perspective of the patient, and responsibility can lead to different attitudes concerning end-of-life decision-making.

Do patients with advanced dementia suffer?

If patients with advanced dementia *can* suffer, a subsequent question is whether or not patients with advanced dementia actually *do* suffer. Chapter 6 reports that NHPs thought that their most recent patient with advanced dementia (n=40) suffered 'unbearably' and 'hopelessly' to some degree in respectively 62% and 74% of the cases, and to a (very) high degree in respectively 26% and 56% of the cases. According to these NHPs, unbearable suffering was most often caused by agitation or confusion, anxiety, pain, progressive deterioration, cramps or contractures, difficulty with breathing, or being afraid as a consequence of not understanding things. If they thought that the suffering was hopeless they most often said that it is was because dementia is progressive and cannot be cured. This implies that the position of the Dutch Association of Nursing Home Physicians (NVVA) does not represent the view of the NHPs in our study: the NHPs frequently thought that their most recent patient with advanced dementia and an advance euthanasia directive did suffer.

A study carried out by Mitchell *et al*, investigating distressing signs and symptoms, supports the concept that patients suffering from advanced dementia can suffer physically (Mitchell *et al.* 2004). They found that patients suffering from dementia were often wrongfully not recognized as terminal patients. Only 1% of nursing home residents were considered to have a life-expectancy of less than 6 months, while 71% died within that period. They compared the symptoms of patients with advanced dementia with those of patients with terminal cancer, and found that some distressing signs and symptoms were reported more often with patients with advanced dementia, such as chewing or swallowing problems (46% vs. 34%), pressure ulcers (15% vs. 6%), fever (13% vs. 7%), and pneumonia (11% vs. 4%), and some were reported less frequently, but still quite often, such as: daily or almost daily pain (12% vs. 57%), shortness of breath (8% vs. 28%), and constipation (14% vs. 33%). With regard to pain, they comment that it is not unlikely that this was under-detected

in the severely demented group. Research has shown that nursing home residents with dementia are less likely to receive pain management than patients with intact cognition (Won *et al.* 1999).

The studies described above indicate that patients with advanced dementia do suffer physically, but that this is often not recognized. However, another aspect of this issue has to be discussed before we can come to any conclusions. There is evidence that pain perception changes with dementia. Benedetti *et al*. found that patients suffering from Alzheimer's disease have a sensory-emotional dissociation, as a result of which they have an increased tolerance for pain. Patients with vascular dementia can either have an increased or a decreased pain tolerance, depending on the localization of the vascular lesions (Benedetti *et al.* 2004; Benedetti, 2004). These results indicate that, for instance, the presence of pressure ulcers as proof of pain, as is implied by the study comparing symptoms of patients with dementia with those of cancer patients, should be interpreted with some caution. However, these results do *not* imply that the pain that is reported by or can be observed in patients with advanced dementia, for instance according to behaviour or facial expression scales, is somehow less severe.

Are physicians willing to comply with advance euthanasia directives of demented patients?

In conclusion, there are indications that patients with advanced dementia can suffer, and that for many demented patients who have advance euthanasia directives, a situation can be identified in which they suffer unbearably and hopelessly. According to the law, an advance euthanasia directive can be followed in such cases. Nevertheless, 54% of the physicians and 74% of the NHPs indicated that they considered it inconceivable they would ever comply with an advance directive of a patient who suffers from dementia. These percentages are much higher than the 11% of physicians and the 12% of NHPs who reported that performing euthanasia in general was inconceivable, mainly on the basis of religious beliefs or a philosophy of life (van der Wal *et al.* 2003).

There appears to be a large gap between the wishes people specify in advance euthanasia directives —72% want euthanasia if they become demented— and the medical practice in nursing homes, where the advance euthanasia directives of demented patients are seldom complied with. The results in Chapter 7 show that 88% of the relatives of patients in the advanced stages of dementia think that advance directives should always be followed, compared with only 37% of the nursing home physicians. This contrast is even greater in the case of advance *euthanasia* directives: 89% of the relatives think that euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent, compared with only 16% of the physicians. A vignette study showed a similar disagreement between physicians and the general population with regard to actively ending the life of a demented patient who has an advance euthanasia directive (Rietjens *et al.* in press).

Expectations for the future

Most people who have an advance euthanasia directive have stated that they want euthanasia if they become demented (NVVE, 2004). As stated by the Royal Dutch Medical Association, although advanced dementia in itself does not meet the requirement of unbearable suffering, it can be met if the patient also has symptoms indicating serious suffering. There are several factors that may lead to an increase in the performance of euthanasia in cases of advanced dementia in the coming years or decades: (1) the fact that since 2002 an advance euthanasia directive has become legally equal to a verbal request for euthanasia, (2) the gap that now exists, as described above, between the wishes people specify in advance directives and current medical practice, (3) an increasing recognition of the frequent occurrence of distressing symptoms that may cause suffering in patients with dementia, (4) the next generation of older people may be more outspoken and more demanding than the present generation, and (5) the NVVE actively advocates that euthanasia should be an option for patients with advanced dementia.

It will be interesting to see how the debate on euthanasia in cases of advanced dementia develops, and how this will affect the legal regulations. The current situation is that advanced dementia can only be a reason for euthanasia if

the patient suffers unbearably and hopelessly, which implies symptoms indicating serious suffering. Although this limitation would appear rational to most people —why would someone want euthanasia if he or she does not suffer?— the NVVE is setting the stakes higher. It can be gathered from their quarterly magazine that they advocate compliance with advance euthanasia directives if a person who has requested euthanasia in case of dementia has become demented, regardless of the further circumstances (Relevant, 2004). The Dutch Alzheimer Foundation takes the opposite position (Relevant, 2004). The Director of the Alzheimer Foundation stated that it does not surprise him that many people mention dementia as a reason for euthanasia on their advance euthanasia directive, because they fear dementia and have a negative image of the available care, but that euthanasia is almost never an issue in practice, because the care is good enough to prevent *en masse* requests. Whether it is the position of the NVVE or the Dutch Alzheimer Foundation that most closely represents the opinions of the general public in the Netherlands remains to be seen.

8.5 RECOMMENDATIONS

The practice of euthanasia started as the only escape in emergency situations in which a patient's suffering was unbearable and hopeless and the physician was not able to ease the suffering to a level that was acceptable for the patient. The first review procedure was based on this type of situation. However, the decision not to limit the possibility of EAS to terminally ill patients had important consequences, and as a result people who do not have a severe disease and who formulate an advance directive for dementia claim the right to EAS. The results presented in this thesis indicate that there is no evidence of large-scale granting of requests for EAS from patients who do not have a severe disease, or who have advanced dementia. However, there is evidence that such cases of EAS do occur, and that such cases are not reported. Thereby, there seems to be a difference between cases that are reported and cases that are not reported, and further indications of this can be found in the diagnoses of patients whose request for EAS was granted. The majority of the cases in which EAS was performed at the request of cancer patients were reported, while only a minority of cases concerning requests from patients with another diagnosis was reported. As the suffering of patients with cancer is often very obvious, it appears that less clear-cut cases are less often reported.

If it is deemed important to check and regulate the practice of EAS in the Netherlands, it could become very problematic if physicians only report their clear-cut cases, especially if the number of cases of EAS in the absence of a severe disease, or in cases of advanced dementia increase. An attempt can be made to prevent this by supporting physicians as much as possible in less clear-cut cases, in which it is more difficult to judge whether the legal requirements are met. If interpretation of the requirements of due care in difficult cases is left to the discretion of individual physicians, and they then have to take the blame if they have interpreted them wrongly, it would be rather naïve to expect physicians to report such cases. It is possible to stimulate prudent practice and the reporting of cases by making clear guidelines for physicians on how to deal with difficult cases. In cases of advanced dementia this would imply the development of criteria to judge whether or not following an advance euthanasia directive is allowed, and in cases of requests for EAS in the absence of a severe disease this would imply further research to provide physicians with tools and information about treatment for patients with a wish to die and improve their chances of success.

Recommendations concerning weariness of life

Research

In most of the cases described in Chapter 2 a brief description of the patient's life history was also provided, and some of these patients had very exceptional lives. The quantitative method of data-collection does not lend itself for accurate analysis of this type of information, and it is therefore possible that justice was not done to the very complex reasons for which people request EAS. Further qualitative research is required to investigate the reasons why people request EAS in the absence of a severe disease.

To weigh up the arguments listed in Table 1 accurately, further research is also required to investigate the occurrence and causes of death wishes in the absence of a severe

disease, the reasons why some of these people with a wish to die request EAS from their physician and others do not, how consistent these death wishes are, and how many people would actually want to take lethal medication. It is important to investigate possibilities to eliminate death wishes or to make them less intense. Treatment aimed at social, physical, psychological or psychiatric problems could be considered, and the willingness of people with a wish to die to try these alternatives, and their chances of success, should be investigated. These issues are not only relevant as requirements of due care if a suicide pill is made available, or if EAS in the absence of a severe disease would be legalized, but also to offer physicians in an ageing society a means to improve the quality of life of older people.

Policy and practice

The legal case against the general practitioner in the Brongersma case seems to have started, rather than concluded, the debate on EAS in the absence of a severe disease. In order to draw an informed conclusion about whether or not EAS in the absence of a severe disease should be allowed, and whether a suicide pill should be made available, answers to the above-mentioned research questions are essential. It would be best to actively gather the necessary information as soon as possible, and not await a new court case concerning EAS in the absence of a severe disease, because that would lead to a judgement pronounced by legal and medical authorities that would depend too much on the circumstances of one single case, instead of on a full understanding of the issue at hand. Until more is known about death wishes and ways to eliminate them or make them less intense, and possible guidelines for treatment can be formulated, physicians will have to deal individually with patients who wish to die and patients who request for EAS in the absence of a severe disease. Of course, if they do not want to be prosecuted, they would be wise to limit themselves to providing treatment and care, and not grant and report requests for EAS in the absence of a severe disease.

Recommendations concerning advance directives

Research

Little is known about what people take into consideration when formulating an advance directive, or the stability of such wishes. Interesting research questions for future research are: Why do people formulate advance directives, for which future situations do they intend their directives, which situations do they want to prevent, do they discuss their advance directives with their relatives and physicians, and do they expect and trust physicians to follow their advance directives? How often does it occur that people change their mind about their advance directive over time, or if they or someone in their surroundings falls ill? It is known that if people fall ill, their ideas of the acceptability of consequences of disease shift. Does this affect the validity of advance directives, formulated when people were healthy? What effect do advance directives have on end-of-life care, and what difficulties are encountered in their use? Answering these questions could be important for accurate evaluation of advance directives. The results could lead to improvement of advance directives to be better applicable in practice, which is in the interest of as well the patient as the physician. Above questions could be addressed by forming and investigating a cohort of people with advance directives, interviewing them about their preferences, reasons and ideas concerning the end-of-life, and observing possible changes, e.g. in case of illness, and interviewing their relatives about the use of their advance directives in case of their death.

Furthermore, it is important to repeat the study of the medical practice as presented in this thesis in order to monitor developments in compliance with advance euthanasia directives of demented patients and in the type of cases in which they are complied with, and to be informed about physicians' experiences in such cases. The estimates in this thesis can be used as a starting point in this respect.

Policy and practice

Is it appropriate to promote the formulation of advance directives in general? It is clear from Chapter 5 that most people who have an advance directive have an advance

euthanasia directive, which is not often followed in practice. Nevertheless, I do think that the formulation of advance directives should be stimulated, because they can be a valuable means to reconstruct the wishes of the patient, even if they do not describe the patient's current situation, and can support the family and physician in difficult situations. It is perhaps even more important to stimulate the correct formulation of advance directives by providing information about the different types of advance directives and their legal value, and the unlikelihood of advance euthanasia directives being followed at present.

If the occurrence of euthanasia in cases of advanced dementia does, indeed, increase in the coming years, the current Article 2.2 of the law will not suffice as a regulation. It only confirms that the requirements of due care still apply, but it does not give any indications as to how these should be interpreted if a patient is incompetent. Since this law was enacted in 2002, no physicians have yet reported any cases in which they have complied with the advance euthanasia directives of a demented patient, but this thesis indicates that it is not unlikely that an unreported practice of complying with advance euthanasia directives of demented patients has already started. Although the type of drugs used (morphine-like drugs) makes it difficult to determine whether or not the life of the patient was actually shortened, and thereby makes it easier to avoid the legal or moral obligation to report the case.

If it is deemed important to check and regulate this practice as it develops, it is necessary to lower the threshold of reporting for physicians, by formulating clear guidelines to which they can adhere. In the Netherlands we can take advantage of the fact that Belgium has now also introduced legislation, to generate ideas to improve our own legislation (See Box 2).

Box 2

In the Belgian law, the rules for euthanasia based on advance directives are specified much more clearly than in the Dutch law. Article 4 specifies requirements that have to be met in cases of euthanasia based on advance directives (Wet betreffende de euthanasie, 2002; Cosyns, 2003). These requirements differ from the requirements for verbal requests. The requirements that have to be met are the following:

- the patient suffers from a severe and incurable illness, caused by accident or disease;
- the patient is unconscious;[b]
- the condition is irreversible, according to current scientific knowledge.

Furthermore, the advance directive also has to meet formal requirements. It has to be drawn up in the presence of two adult witnesses, at least one of whom must have no material interest in the death of the patient. The patient and the witnesses have to date and sign the advance directive. The advance directive can only be complied with if it was drawn up or confirmed less than five years before the patient became unable to express his/her will. This Belgian law only applies if a patients is unconscious, so it does not apply in cases of dementia. Whether or not euthanasia in cases of dementia should be allowed is still a subject of debate in Belgium (De Lepeleire *et al.* 2004).

[b] Interestingly, in the Belgian law unconsciousness is a requirement and unbearable suffering is not a requirement in the case of incompetence. This is the exact opposite of the Dutch law, for which unbearable suffering is an important foundation, and a state of unconsciousness thereby excludes the possibility of EAS.

Although these specific regulations would not be appropriate in the light of the current legislation in the Netherlands, this Article of the Belgian law provides some suggestions for guidelines for euthanasia in cases of advanced dementia. For example, it is obvious that separate regulations applying to the specific situation of incompetence are much easier to interpret for physicians. For a Belgian physician it is quite clear which requirements must be met for legal life-termination. Furthermore, the time-limit of the advance directive, and the presence and signatures of witnesses could ensure that advance directives are taken seriously by both the physician and the patient.

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LIST OF ABBREVIATIONS

AD	Advance Directive
ANH	Artificial Nutrition and Hydration
CI	Confidence Interval
DPA(HC)	Durable Power of Attorney (for Health Care)
EAS	Euthanasia or Assisted Suicide
GP	General Practitioner
LASA	Longitudinal Aging Study Amsterdam
N	Number
NHP	Nursing Home Physician
NIVEL	Netherlands Institute for Health Services Research
NVVA	Dutch Association of Nursing Home Physicians
NVVE	Dutch Association for Voluntary Life-termination
OR	Odds Ratio
P	Probability
PAS	Physician-Assisted Suicide
RDMA	Royal Dutch Medical Association (KNMG)
RR	Relative Risk
SCEN	Support and Consultation with Euthanasia in the Netherlands

GLOSSARY ENGLISH-DUTCH

Advance directive	Wilsverklaring
Advance euthanasia directive	Euthanasieverklaring
Clinical specialist	Medisch specialist
General practitioner	Huisarts
Nursing home	Verpleeghuis
Nursing home physician	Verpleeghuisarts
Physician-Assisted Suicide	Hulp bij zelfdoding
Tired of living	Levensmoe
Weary of life	Klaar met leven

SUMMARY

In the Netherlands, euthanasia has become an accepted practice over the past few decades. It has become endorsed by law, the medical profession and public opinion. Although euthanasia and physician-assisted suicide (EAS) are still subject to the Penal Code, since 2002 EAS is no longer punishable if the physician meets the so-called requirements of due care. These stipulate that the patient's request must be voluntary and well-considered, the physician must be convinced that the patient's suffering is unbearable and hopeless, the physician must inform the patient about his/her situation and prospects, and together they come to the conclusion that there is no other reasonable solution. Furthermore, an independent physician must be consulted, the EAS must be performed with due care, and the physician must report the performance of EAS to the coroner. The terminal phase of a disease has never been included as a requirement of due care in the euthanasia legislation, and there are consequences of the absence of a terminal phase that have led to much debate in the Netherlands: should euthanasia be allowed in the absence of a disease, if people are 'weary of life', and should euthanasia be allowed in the case of advanced dementia if the patient has an advance euthanasia directive? However, although the debate on these issues is ongoing, it is mainly theoretical. The aim of this thesis is to analyze the practice of EAS in the absence of a disease and in the case of advanced dementia, and to provide information to advance the debate. To achieve this aim, not only the occurrence of (requests for) EAS in the absence of a disease and in the case of advanced dementia was investigated, but also several closely related issues, such as being 'tired of living', a 'suicide pill', and the prevalence of advance directives. By means of interviews with physicians, insight was obtained into the incidence of requests made in the absence of a severe disease and in the case of advanced dementia (by means of an advance directive), and the experiences of the physicians in such cases. Furthermore, data were collected to investigate the attitudes of physicians and the general population in the Netherlands concerning these issues.

Methods of research

This thesis was originally based on a study that was part of a large-scale study to evaluate the review procedure for EAS (1a,b,c). However, the present thesis was enriched with data from other studies focussing on similar subjects (2,3,4). Below a broad overview is given of the methods of research.

1. *Evaluation of the review procedure for EAS*
   a) *Physician interviews (Chapters 2, 4, 6):* In 2002 a random sample of general practitioners (*n*=125), nursing home physicians (*n*=77), and clinical specialists (cardiologists, surgeons and specialists in internal medicine, pulmonology and neurology) (*n*=208) were interviewed. They were retrospectively interviewed by trained physicians and asked about their experiences with requests for EAS from older people who did not have a severe disease and demented patients with an advance euthanasia directive. Of the 482 physicians who were selected for this study, 72 (15%) were unwilling to participate, mostly due to a lack of time.
   b) *General population questionnaires (Chapters 4, 5):* In September 2002, 1,379 people in the general population completed a questionnaire. These people were participants in an existing consumer panel selected by the NIVEL (Netherlands Institute for Health Services Research), as representative of the population in the Netherlands above the age of 18 years. The response was 78%.
   c) *Interviews with relatives (Chapters 4, 5):* In 2002 87 relatives of patients who had died after EAS were interviewed. The relatives were selected through a sample of 167 physicians who had reported EAS to a Regional Review Committee in 2001 or 2002. These physicians were asked to contact the relative who had been most involved in caring for the patient, and to ask them if they would be willing to be interviewed about their experiences and attitudes. Of the 97 relatives (58%) who were

contacted, 87 relatives (90%) agreed to be interviewed.

2. *SCEN questionnaires for general practitioners (Chapter 3):* The data presented in Chapter 3 of this thesis were derived from a study that was designed to evaluate the project 'Support and Consultation on Euthanasia in the Netherlands' (SCEN), which is a network of specifically trained physicians from whom general practitioners can obtain information or request consultation. For the evaluation of this project it was necessary to collect data before and after the implementation of SCEN. This resulted in 1,227 completed questionnaires in the 'pre-test'(response 70%) in 2000/2001, and 3,615 completed questionnaires in the 'post-test' (response 60%) in 2001/2002. The part of the questionnaires that is relevant for this thesis is that in which the general practitioners were asked to describe their most recent case in which a patient had requested EAS. Because the implementation of SCEN is not relevant for this thesis, the requests described in the pre-test were added to those described in the post-test. A selection was made of patients for whom being tired of living played a major role in their request for EAS.
3. *LASA interviews with older people (Chapter 5):* The data concerning older people were derived from the 'Longitudinal Aging Study Amsterdam' (LASA). The respondents in this study are interviewed every three years. Chapter 5 is based on interviews in '98—'99 with 1,874 people between 61 and 92 years of age, because in that year more extensive questions were asked about end-of-life preferences.
4. *Artificial nutrition and hydration questionnaires (physicians, nurses and relatives) (Chapter 7):* The data were derived from a study investigating artificial nutrition and hydration in nursing home patients with dementia, in which questionnaires were completed by 107 physicians, 148 nurses and 136 relatives of the patients for whom a decision concerning artificial nutrition and hydration was made. Chapter 7 presents data from the responses to 15 statements about artificial nutrition and hydration, advance directives, hastening death, self-determination and euthanasia, and nursing home policy.

Outline of this thesis

The thesis is divided into four parts. In Part 1 the general concepts of EAS and the current regulations from the perspective of the themes of the thesis are introduced (Chapter 1). Part 2 consists of three chapters (Chapters 2—4) which address several issues that are related to being 'weary of life', and Part 3 consists of three chapters (Chapters 5—7) concerning several issues that are related to advance directives. This is followed by a General Discussion in Part 4 (Chapter 8).

Main findings

Chapter 2 presents the results of a physician interview study concerning requests for EAS from older persons who do not have a severe disease. It was found that, in the Netherlands, each year approximately 400 people request EAS because they are 'weary of life'. Thirty percent of all physicians (n=410) had at some time received an explicit request for EAS in the absence of a severe disease, and 3% of all physicians had granted a request for EAS in such a case. Most of the requests that were made to general practitioners for EAS in the absence of severe disease (n=29) were made by single people aged 80 and over. Although their problems were most frequently of a social nature, 79% had one or more non-severe illnesses. Most of the general practitioners refused such requests; half of them proposed an alternative treatment, which the patient often refused. Nineteen people who did not receive any treatment persisted in their wish to die; the request for EAS from 5 out of 10 patients who received one or more types of treatment was withdrawn or became less explicit.

Chapter 3 reports that, according to the physicians, 17% of the 2,419 patients who requested EAS were 'tired of living'. Of the 139 patients for whom tired of living played a major role in their request for EAS, 47% suffered from cancer, 25% suffered from another severe disease, and 28% had no severe disease. In all three groups the same three symptoms occurred most frequently, 'feeling bad', 'being very tired', and 'not being active'. Each of these symptoms occurred in more than half of the patients in each group. Women were over-represented in these requests (62%), especially in the

absence of a severe disease (90%). Most of the requests from patients with cancer were granted, but those from patients who had some other type of severe disease, or no severe disease at all, were most often refused. Factors that were related to granting a request were the presence of unbearable and hopeless suffering, the absence of alternatives, and the absence of depressive symptoms.

In Chapter 4 it is clear that most of the physicians, the general public and the relatives were of the opinion that everybody should have the right to decide about their own life and death. Compared to the physicians, the general public and the relatives were more in favor of enabling older people to obtain medication to end their life if they so wish. Furthermore, 15% of the general public and 36% of the relatives thought that a 'suicide pill' should be made available. The reason why the relatives thought that a suicide pill should be made available was the right to decide about one's own life and death. The main reasons for being against the suicide pill were "fear of taking such a pill when depressed or on impulse" (42%), and "a preference for the involvement of a physician" (30%). In all groups, religious beliefs were associated with a less supportive attitude towards self-determination at the end of life. Of the physicians, 74% considered it inconceivable that they would ever grant a request for EAS in the absence of a severe disease.

Chapter 5 describes the frequency and determinants of advance directives concerning end-of-life care. The determinants were arranged according to the three following components: predisposing factors (e.g. age, gender), enabling factors (e.g. education) and need factors (health-related factors). We found that living wills had been formulated by 3% of people up to 60 years of age, 10% of people over 60 years of age, and 23% of the relatives of a person who died after EAS. Most living wills concerned a request for euthanasia. In all groups, 26—29% had authorized someone to make decisions if they were no longer able to do so themselves. Talking to a physician about medical end-of-life treatment occurred less frequently; only 2% of the younger people and 7% of the older people had done so. Most people were quite confident that the physician would respect their end-of-life wishes, but older people more so than younger people. In a multivariate analysis, many predisposing factors were associated with the formulation of an advance directive: women, older people, non-religious people —especially those who lived in an urbanized area— and people with less confidence that the physician would respect their end-of-life wishes were more likely to have formulated an advance directive. Furthermore, the enabling factor of a higher level of education, the need factor of contact with a medical specialist in the past 6 months, and the death of a marital partner were associated with the formulation of an advance directive.

Chapter 6 describes the experiences of physicians in the Netherlands with demented patients with an advance euthanasia directive. Approximately 2,200 demented patients with an advance euthanasia directive died annually in 2000 and 2001, after being treated by a physician who knew about this directive. In 76% of such cases compliance with the directive was discussed, but euthanasia was seldom performed. In two thirds of the cases of demented nursing home patients with an advance euthanasia directive the physician could identify during the course of the disease a situation for which the patient had intended the directive. In such cases, a quarter of the nursing home physicians thought that in their most recent case the patient suffered unbearably, and half of them thought that the patient suffered hopelessly. In three quarters of the cases the relatives did not want the nursing home physician to comply with the directive, but they did want to respect the patient's wishes by foregoing life-prolonging treatment. This occurred in 9 out of 10 cases.

Chapter 7 describes the attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. Factors that could influence their attitudes were investigated. In general, physicians, nurses and relatives agree on many aspects of end-of-life decision-making for nursing home patients with dementia. However, on some issues the opinions differed. Relatives attach more importance to advance directives than

physicians, and have more permissive attitudes towards hastening death. Although physicians, nurses and relatives are all guided by the best interest of the patient, it seems that differences in religious beliefs, the perspective of the patient, and responsibility can lead to different attitudes towards end-of-life decision-making.

Chapter 8 is the final chapter of this thesis, in which the findings are placed in a broader perspective. Relevant issues, such as whether or not people who request EAS in the absence of a disease suffer from clinical depression, whether or not such requests pertain to the medical domain, the conclusions of the 'Committee Dijkhuis', arguments in favor of and against a suicide pill, and the question of whether or not patients with advanced dementia suffer, are discussed in the light of the results of this thesis.
Some recommendations for research, policy and practice are also made in this Chapter. For instance, further research is required to investigate the occurrence of death wishes, their durability, the reasons why people wish to die, and the possibilities to eliminate death wishes or to make them less intense. These issues are not only relevant as requirements of due care if a suicide pill is made available, or if EAS in the absence of a severe disease would be legalized, but also to offer physicians in an ageing society a means to improve the quality of life of older people with a wish to die.
Another recommendation that is made is that clear guidelines should be formulated to assist physicians in their assessment of whether or not an advance euthanasia directive of a patient with advanced dementia can be complied with. Although complying with such directives can be legal according to Article 2.2 of the EAS legislation, and the results of this thesis show that physicians do sometimes comply with such directives, no physicians have yet reported any such cases of euthanasia to the proper authorities. It seems that this Article does not suffice as a regulation. It only confirms that the requirements of due care still apply, but it does not give any indications as to how these should be interpreted if a patient is incompetent. If it is deemed important to check and regulate the practice of EAS as it develops, it is necessary to lower the threshold of reporting for physicians, e.g. by clarifying the regulations in guidelines.

DUTCH SUMMARY

In de laatste decennia is euthanasie in Nederland een geaccepteerde praktijk geworden: in het recht, de medische professie en de publieke opinie. Alhoewel euthanasie en hulp bij zelfdoding (EHBZ) nog steeds vallen onder het strafrecht, is EHBZ niet meer strafbaar sinds 2002, mits aan de zogenaamde zorgvuldigheidseisen voldaan is. Hierin staat dat er een vrijwillig en weloverwogen verzoek van de patiënt moet zijn, er moet naar de overtuiging van de arts sprake zijn van ondraaglijk en uitzichtloos lijden, de arts moet de patiënt voorlichten over diens situatie en vooruitzichten en samen moeten zij tot de conclusie komen dat er geen redelijke andere oplossing is. Tevens moet er een onafhankelijke arts worden geconsulteerd en moet de EHBZ medisch zorgvuldig uitgevoerd worden en gemeld bij de gemeentelijk lijkschouwer. Het terminale stadium van een ziekte is nooit opgenomen als zorgvuldigheidseis in de euthanasiewetgeving en er zijn gevolgen van de afwezigheid van een dergelijk criterium die tot veel discussie hebben geleid in Nederland: moet euthanasie worden toegestaan in afwezigheid van een ernstige ziekte, als mensen 'klaar met leven' zijn? En moet euthanasie toegestaan worden in geval van vergevorderde dementie als de patiënt in het bezit is van een euthanasieverklaring? Alhoewel het debat over deze onderwerpen voortduurt, is dit debat vooral theoretisch. De doelstelling van dit proefschrift is de praktijk van EHBZ in afwezigheid van ziekte en in geval van vergevorderde dementie te analyseren en informatie aan te leveren om het debat vooruit te helpen. Ten behoeve van deze doelstelling werd niet alleen het vóórkomen van (verzoeken om) EHBZ in afwezigheid van een ziekte en in geval van vergevorderde dementie onderzocht, maar ook een aantal nauwverwante thema's, zoals levensmoeheid, de 'pil van Drion' en het vóórkomen van wilsverklaringen. Door middel van het interviewen van artsen werd inzicht verkregen in hoe vaak patiënten een verzoek doen bij hun arts in afwezigheid van een ziekte, in het geval van vergevorderde dementie (door middel van een wilsverklaring) en in de ervaringen van de artsen in zulke gevallen. Tevens werden gegevens verzameld om de meningen van artsen en de bevolking in Nederland aangaande deze thema's te onderzoeken.

Methoden van onderzoek

Dit proefschrift was oorspronkelijk gebaseerd op een onderzoek dat onderdeel was van een grootschalig onderzoek dat was ingesteld om de toetsingsprocedure EHBZ te evalueren (1a,b,c). Echter, dit proefschrift is verrijkt met gegevens uit andere studies naar vergelijkbare onderwerpen (2,3,4). Hieronder wordt een globale indruk gegeven van de onderzoeksmethoden.

1. *Evaluatie van de toetsingsprocedure EHBZ*
   a) *Artseninterviews (Hoofdstukken 2, 4, 6)*: In 2002 werd d.m.v. een steekproef een aselecte groep huisartsen(n=125), verpleeghuisartsen (n=77) en specialisten (cardiologen, chirurgen, internisten, longartsen en neurologen) (n=208) geïnterviewd. Speciaal getrainde artsen interviewden deze artsen retrospectief over hun ervaringen met verzoeken om EHBZ van ouderen die geen ernstige ziekte hadden en met demente patiënten met een euthanasieverklaring. Van de 482 artsen die werden geselecteerd voor dit onderzoek, weigerden 72 (15%) deelname, meestal door een gebrek aan tijd.
   b) *Vragenlijsten Nederlandse bevolking (Hoofdstukken 4, 5*): In september 2002 vulden 1379 mensen uit de Nederlandse bevolking een vragenlijst in. Deze mensen waren deelnemers in een bestaand consumentenpanel van het NIVEL (Nederlands instituut voor onderzoek van de gezondheids-zorg). Dit panel was representatief voor de Nederlandse bevolking ouder dan 18 jaar. De respons was 78%.
   c) *Interviews met nabestaanden (Hoofdstukken 4, 5):* In 2002 werden 87 nabestaanden van patiënten die overleden waren na EHBZ geïnterviewd. De nabestaanden werden benaderd via de arts die de EHBZ had gemeld bij de Regionale Toetsings-commissies Euthanasie in 2001 of 2002. Deze artsen werd gevraagd contact op te nemen met de nabestaande die het meest betrokken was bij de zorg voor de patiënt en deze nabestaande te

vragen of hij of zij bereid was geïnterviewd te worden over hun ervaringen en mening. Van de 97 nabestaanden (58%) waar contact mee werd opgenomen door de arts, werden er 87 (90%) geïnterviewd.

2. *SCEN vragenlijsten huisartsen (Hoofdstuk 3):* De gegevens die in hoofdstuk 3 van dit proefschrift worden gepresenteerd zijn afkomstig uit een onderzoek dat was opgezet om het project 'Steun en Consultatie bij Euthanasie in Nederland'(SCEN) te evalueren. SCEN is een netwerk van speciaal getrainde artsen waar huisartsen informatie of een consultatie kunnen aanvragen. Om dit project te evalueren was het nodig om voor en na de implementatie van SCEN gegevens te verzamelen. Voor de implementatie werden 1227 vragenlijsten ingevuld (respons 70%) in 2000/2001, na de implementatie werden 3615 vragenlijsten ingevuld (respons 60%) in 2001/2002. Het deel van de vragenlijst dat relevant is voor dit proefschrift, is dat waarin huisartsen werden gevraagd het laatste verzoek om EHBZ te beschrijven. Omdat de implementatie van SCEN niet relevant is voor dit proefschrift, werden de verzoeken beschreven voor en na de implementatie bij elkaar opgeteld. Een selectie werd gemaakt van patiënten voor wie 'levensmoeheid' een grote rol speelde bij het verzoek.
3. *LASA interviews met ouderen (Hoofdstuk 5):* De gegevens van oudere mensen zijn afkomstig uit het 'Longitudinale verouderingsonderzoek Amsterdam' (LASA). De respondenten in dit onderzoek worden elke drie jaar geïnterviewd. Hoofdstuk 5 is gebaseerd op de interviews uit '98—'99 met 1874 mensen tussen de 61 en 92 jaar. In dat jaar werden uitgebreidere vragen gesteld over voorkeuren aan het levenseinde.
4. *Vragenlijsten kunstmatige vocht en voedsel (artsen, verzorgenden en familie) (Hoofdstuk 7):* De gegevens zijn afkomstig uit een *onderzoek* naar kunstmatige toediening van vocht en voedsel bij demente patiënten in verpleeghuizen, waarvoor vragenlijsten werden ingevuld door 107 artsen, 148 verzorgenden en 136 familieleden van patiënten waarbij een beslissing genomen was over het al dan niet kunstmatig toedienen van vocht en voedsel. In hoofdstuk 7 worden de gegevens gepresenteerd van de meningen over 15 stellingen over kunstmatige vocht en voeding, wilsverklaringen, het bespoedigen van de dood, zelfbeschikking en euthanasie, en het verpleeghuisbeleid.

Opzet van het proefschrift

Dit proefschrift bestaat uit vier delen. In deel 1 worden de algemene concepten van EHBZ en de huidige regelingen vanuit het perspectief van de onderwerpen van dit proefschrift geïntroduceerd (Hoofdstuk 1). Deel 2 bestaat uit drie hoofdstukken (Hoofdstukken 2—4) die verschillende onderwerpen gerelateerd aan 'klaar-met-leven' zijn behandelen en deel 3 bestaat uit drie hoofdstukken (Hoofdstukken 5—7) die gaan over verschillende onderwerpen gerelateerd aan wilsverklaringen. Deel 4 (Hoofdstuk 8) bevat de algemene discussie.

Belangrijkste bevindingen

Hoofdstuk 2 presenteert de resultaten van de interviews met artsen wat betreft de verzoeken om EHBZ van ouderen die geen ernstige ziekte hebben. Uit dit onderzoek blijkt dat in Nederland jaarlijks ongeveer 400 mensen verzoeken om EHBZ omdat ze 'klaar-met-leven' zijn. Dertig procent van alle artsen (n=410) had ooit een uitdrukkelijk verzoek om EHBZ gekregen van een patiënt die geen ernstige ziekte had en 3% van alle artsen had ooit een dergelijk verzoek ingewilligd. De meeste verzoeken om EHBZ die werden gedaan aan huisartsen in de afwezigheid van ernstige ziekte (n=29) werden gedaan door alleenstaande mensen in de leeftijd van 80 jaar en ouder. Alhoewel hun problemen meestal van een sociale aard waren, had 79% een of meer niet-ernstige aandoeningen. De meeste huisartsen weigerden zulke verzoeken, de helft van hen stelde een alternatieve behandeling voor, welke door de patiënt vaak werd geweigerd. Negentien mensen die geen alternatieve behandeling kregen volhardden in hun wens om te sterven; 5 van de 10 patiënten die wel één of meer behandelingen kregen matigden hun verzoek of trokken het in.

Hoofdstuk 3 rapporteert dat, volgens de artsen, 17% van de 2419 patiënten die een verzoek om EHBZ deden 'levensmoe' was. Van de 139 patiënten voor wie 'levensmoeheid' een grote rol speelde in hun verzoek om EHBZ, leed 46% aan kanker, 25% aan een andere ernstige ziekte, en 28% had geen ernstige ziekte. In elk van de drie groepen kwamen dezelfde drie symptomen het meeste voor, "zich slecht voelen", "erg moe zijn" en "niet actief zijn". Elk van deze symptomen kwam voor bij meer dan de helft van de patiënten in elke groep. Vrouwen waren oververtegenwoordigd in deze verzoeken (62%), vooral in de afwezigheid van ernstige ziekte (90%). De meeste verzoeken van patiënten die kanker hadden werden ingewilligd, maar verzoeken van patiënten die een andere ernstige ziekte hadden, of die helemaal geen ernstige ziekte hadden, werden meestal geweigerd. Factoren die geassocieerd waren met het inwilligen van een verzoek waren de aanwezigheid van ondraaglijk en uitzichtloos lijden, de afwezigheid van alternatieven en de afwezigheid van depressieve symptomen.

In hoofdstuk 4 wordt duidelijk dat het merendeel van de artsen, de Nederlandse bevolking en de nabestaanden van mening waren dat iedereen het recht zou moeten hebben om zelf te beschikken over leven en dood. In vergelijking met de artsen, vonden de mensen uit de Nederlandse bevolking en de nabestaanden vaker dat oudere mensen in staat moeten worden gesteld middelen te verkrijgen waarmee zij op een door henzelf te bepalen moment een einde aan hun leven kunnen maken als zij dat willen. Verder vond 15% van de Nederlandse bevolking en 36% van de nabestaanden dat een 'zelfdodingspil' beschikbaar moet komen. De reden waarom de nabestaanden vonden dat een zelfdodingspil beschikbaar moet komen was dat iedereen het recht zou moet hebben om te beschikken over het eigen leven en de dood. De belangrijkste redenen tegen beschikbaarheid van een zelfdodingspil waren "angst om zo'n pil impulsief of op een depressief moment te slikken" (42%) en "een voorkeur voor de betrokkenheid van een arts" (30%). In alle groepen was het hebben van een geloofsovertuiging geassocieerd met een minder positieve houding tegenover zelfbeschikking aan het levenseinde. Voor 74% van de artsen was het ondenkbaar dat ze ooit een verzoek om EHBZ van een patiënt die geen ernstige ziekte had, zouden inwilligen.

Hoofdstuk 5 beschrijft het voorkomen en de determinanten van wilsverklaringen aangaande zorg aan het levenseinde. De determinanten werden gerangschikt naar de drie volgende componenten: aanleg factoren (bijv. leeftijd en geslacht), in staat stellende factoren (bijv. opleiding) en behoefte factoren (gezondheidsgerelateerde factoren). Van de mensen tot 60 jaar had 3% een wilsverklaring opgesteld, van de mensen ouder dan 60 jaar had 10% een wilsverklaring en 23% van de nabestaanden van iemand die was overleden na EHBZ had een wilsverklaring. De meeste wilsverklaringen betroffen een verzoek om euthanasie. In alle groepen had 26—29% een vertegenwoordiger benoemd om beslissingen te nemen als ze daar zelf niet meer toe in staat zouden zijn. Minder vaak kwam het voor dat mensen met hun arts spraken over medische behandelingen aan het levenseinde; slechts 2% van de mensen tot 60 jaar en 7% van de oudere mensen had dit gedaan. De meeste mensen hadden tamelijk tot zeer veel vertrouwen dat de arts hun wensen over behandelingen aan het levenseinde zou volgen, maar oudere mensen hadden meer vertrouwen dan jongere mensen. In een multivariate analyse bleken vele aanleg factoren geassocieerd te zijn met het opstellen van een wilsverklaring: vrouwen, ouderen, mensen zonder geloofsovertuiging —vooral zij die in een stedelijke omgeving woonden— en mensen die er minder vertrouwen in hadden dat de arts hun wensen over behandelingen aan het levenseinde zou volgen, hadden vaker een wilsverklaring. Verder hadden mensen vaker een wilsverklaring als ze een hogere opleiding hadden (in staat stellende factor) of als ze bij een medisch specialist waren geweest in de laatste 6 maanden (behoefte factor), of als hun huwelijkspartner was overleden.

Hoofdstuk 6 beschrijft de ervaringen van artsen in Nederland met demente patiënten met een euthanasie-verklaring. Ongeveer 2200 demente patiënten met een euthanasieverklaring overleden jaarlijks in 2000 en 2001, na behandeld te zijn door een arts die wist van de euthanasieverklaring. In 76% van zulke gevallen was het al dan niet opvolgen van de wilsverklaring besproken, maar

euthanasie was zelden uitgevoerd. In tweederde van de gevallen van demente verpleeghuispatiënten met een euthanasieverklaring kon de arts een situatie aanwijzen in de loop van het ziekteproces waarvoor de patiënt de euthanasieverklaring bedoeld had. In zulke gevallen dacht een kwart van de verpleeghuisartsen in hun recentste geval dat de patiënt ondraaglijk leed, en de helft dacht dat de patiënt uitzichtloos leed. In driekwart van de gevallen wilden de naasten niet dat de verpleeghuisarts de euthanasieverklaring zou inwilligen, maar wilden ze dat de verpleeghuisarts de wensen van de patiënt zou volgen door van levensverlengende behandelingen af te zien. Dit gebeurde in 9 van de 10 gevallen.

Hoofdstuk 7 beschrijft de houdingen van artsen, verzorgenden en naasten ten opzichte van beslissingen aan het levenseinde van demente verpleeghuispatiënten. Factoren die hun houdingen konden beïnvloeden werden onderzocht. Over het algemeen waren artsen, verzorgenden en naasten het eens over vele aspecten van beslissingen aan het levenseinde van demente verpleeghuispatiënten. Echter, op sommige punten verschilden de meningen. Naasten hechten meer waarde aan wilsverklaringen dan artsen en hebben een tolerantere houding ten opzichte van bespoediging van het levenseinde. Alhoewel artsen, verzorgenden en naasten allen geleid worden door het belang van de patiënt, lijkt het dat verschillen in geloofsovertuiging, wijze van beschouwing van de patiënt en verantwoordelijkheid kunnen leiden tot verschillende opvattingen over besluitvorming aan het levenseinde.

Hoofdstuk 8 is het laatste hoofdstuk van dit proefschrift, waarin de bevindingen in een breder perspectief worden geplaatst. Relevante onderwerpen, zoals of mensen die geen ernstige ziekte hebben en een verzoek doen om EHBZ aan een klinische depressie lijden, of zulke verzoeken behoren tot het medisch domein, de conclusies van de Commissie Dijkhuis, argumenten voor en tegen een zelfdodingspil en de vraag of patiënten met vergevorderde dementie lijden, worden besproken in het licht van de resultaten van dit proefschrift.
Bovendien worden in dit hoofdstuk enkele aanbevelingen gedaan voor onderzoek, beleid en praktijk. Bijvoorbeeld is meer onderzoek nodig naar het vóórkomen van wensen om te sterven, de duurzaamheid van die verzoeken, de redenen waarom mensen een wens om te sterven hebben, en de mogelijkheden om wensen om te sterven te elimineren of minder intens te maken. Deze onderwerpen zijn niet alleen relevant als zorgvuldigheidseisen als een zelfdodingspil beschikbaar gemaakt zou worden of als EHBZ in de afwezigheid van ernstige ziekte gelegaliseerd zou worden, maar ook om artsen in een verouderende maatschappij mogelijkheden te bieden om de kwaliteit van leven van ouderen met een wens om te sterven te verbeteren.
Een andere aanbeveling die wordt gedaan is dat duidelijke richtlijnen geformuleerd moeten worden waarvan artsen gebruik kunnen maken bij het beoordelen of een euthanasieverklaring van een demente patiënt al dan niet ingewilligd kan worden. Alhoewel het inwilligen van een dergelijke euthanasieverklaring legaal kan zijn volgens Artikel 2.2 van de euthanasiewet en de resultaten van dit proefschrift aantonen dat artsen dergelijke verklaringen soms inwilligen, heeft nog geen enkele arts een dergelijk geval van euthanasie bij de bevoegde instanties gemeld. Het lijkt erop dat dit Artikel niet voldoet als reglement. Het bevestigt alleen dat de zorgvuldigheidseisen nog van toepassing zijn, maar het geeft geen aanwijzingen wat betreft hoe die zorgvuldigheidseisen geïnterpreteerd moeten worden als de patiënt wilsonbekwaam is. Als het van belang wordt geacht om de praktijk van EHBZ te controleren en te reguleren naarmate die zich ontwikkeld, is het noodzakelijk om de drempel voor artsen om te melden te verlagen, bijvoorbeeld door het opheldering van de reglementen door middel van richtlijnen.

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